University of Alberta

The Role of Family Support in Promoting Adherence to Tuberculosis Treatment in Western Uganda

by

Michelle Lynn Tubman

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ABSTRACT

This objective of this study was to determine whether family support plays an important role in promoting adherence to tuberculosis (TB) treatment. A questionnaire was administered to 207 families in the Kabarole district of western Uganda and was aimed at determining the knowledge, attitude, and supportive behaviour regarding TB within the family. In-depth interviews were also conducted with TB patients, their families, and health care staff involved in TB control services. It was shown that knowledge of TB disease, its causation, and transmission are low. Attitudes regarding TB generally reflected the social stigma attached to TB in Africa, and few families exhibited supportive behaviour towards the TB patient and his/her family. There were generally no significant differences in measures of knowledge, attitude, or support between families of TB patients who completed their treatment and families of patients who did not. TB remains a serious health issue in western Uganda.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
BHS	Basic Health Services
CA	Constitutional Assembly
CB-DOTS	Community-based DOTS
CHW	Community Health Worker
DOTS	Directly Observed Therapy, short course
DTLS	District TB and Leprosy Supervisor
EP	Extra-pulmonary
HIV	Human Immunodeficiency Virus
IUATLD	International Union Against Tuberculosis and Lung Disease
LC II	Local Council II
LTBI	Latent TB Infection
MOH	Ministry of Health
NCC	National Consultative Commission
NGO	Non-governmental Organization
NHS	National Health Service
NLTP	National Leprosy and Tuberculosis Programme
NRA	National Resistance Army
NRM	National Resistance Movement
PDC	Parish Development Committee
RC	Resistance Council
RCT	Randomized Controlled Trial
TB	Tuberculosis
UNLF	Uganda National Liberation Front
UPC	Uganda People's Congress
USAID	United States Agency for International Development
UPE	Universal Primary Education
WHO	World Health Organization
ZTLS	Zonal TB and Leprosy Supervisor

CHAPTER 1 – INTRODUCTION

The magnitude of the global tuberculosis (TB) epidemic is staggering, making it one of the most important endemic of humankind. In 1993, the World Health Organization (WHO) declared TB a global emergency, becoming the first disease to be designated as such by WHO. It has been estimated that in 1997, eight million incident cases of TB occurred, including 3.5 million cases of smear-positive, infectious pulmonary disease. Also in that year, 1.9 million people died of TB. The average case fatality rate was 23%, but exceeded 50% in some African countries. A total of 1.9 billion people, or 32% of the global population, was infected with *Mycobacterium tuberculosis*. 10.7 million of those people were co-infected with the human immunodeficiency virus (HIV). If worldwide control of TB does not improve, the annual incidence of TB is expected to increase by 41% by 2020, making more than 10 million people ill with TB each year (Emili 2001). These estimates are based on notification data and, because of the underreporting of TB cases, are conservative estimates at best (Dolin 1994).

Much of this predicted increase in incidence will result from demographic factors, such as population growth and a changing structure of the population (Dolin 1994). However, in sub-Saharan Africa, epidemiological factors, primarily the HIV epidemic, will be largely responsible for this increase (Dolin 1994).

Ninety five percent of all new cases and 98% of all TB deaths occur in the developing world, predominantly in Asia and Africa (Emili 2001). This causes a tremendous social and economic burden, compounded by the age distribution of TB. The incidence of TB is concentrated in adults of reproductive age (15 to 49 years) (Murray 1990). This represents the parents, community leaders, producers, and the most economically active groups in many societies. The TB epidemic in developing countries is also worsened by the concurrent HIV epidemic. HIV has been recognized as being the most potent risk factor for developing active TB disease in individuals infected with *M. tuberculosis*. Because of the dramatic incidence of TB, its significant morbidity and mortality, and its effect on both individuals and society, this disease remains a global public health emergency.

However, in developed and developing countries alike, TB primarily affects the poor, whose voices have been routinely silenced and unheard. TB is a social disease as much as it is a medical one. The development of effective anti-tuberculosis treatment was hailed as the

beginning of the end of TB (Farmer 1991). But the social aspect of this disease has never been adequately addressed. Indeed, the advent of TB treatment has enlarged inequalities both locally and globally: the "TB outcome gap" between rich and poor grew, as did the outcome gap between rich countries and poor countries (Farmer 1991). This "forgotten plague" is very much a part of every day life in developing countries. Although TB is so strongly tied to poverty and inequality, experience shows that even modest interventions can have dramatic effects on treatment outcome. This study was designed to give a voice to those affected by this disease the most and to identify strategies to help improve the health and quality of life of these people.

1.1 TB Control

Because the main reservoir of TB is humans, the most efficient method of controlling the transmission of this disease is to reduce the number of TB cases within the community, particularly active, infectious TB cases. The reservoir of TB includes all latently infected people at risk of developing active TB. When TB reactivates in these individuals, they may become infectious. Left untreated, each infectious case can infect 12 to 14 other people each year (Centres for Disease Control and Prevention 2000). Of these newly infected contacts, 5 to 10% of them will develop primary TB within two years, and the remainder will add to the reservoir pool of latently infected people at risk of later reactivation. TB differs from many other public health problems in that if those with active TB are given poor treatment, the result (from a public health perspective) is worse than no treatment at all. It may result in cases remaining as sources of infection in the community longer than if they had experienced the natural history of untreated disease. Poor treatment also often causes drug resistance which immensely complicates management of the individual and ultimately, control in the community.

Therefore, control strategies for TB must be based on the diagnosis and treatment of all sources of infection. Identifying and treating active, infectious (smear-positive), pulmonary cases renders them non-infectious and therefore unable to continue transmitting the disease to others. Because effective treatment breaks the cycle of transmission, cure is the best prevention.

TB is a treatable, curable disease. Effective and affordable, although less than ideal, tools for detecting, treating, and preventing TB are available: sputum smear microscopy and chemotherapy with anti-tuberculosis drugs. However, the WHO recognizes that much of our failure in successfully controlling TB results from inadequate utilization of these available tools. Problems may arise in case-finding and diagnosis, the supply of drugs, and the organization and

administration of chemotherapy. However, it is widely acknowledged that poor patient adherence to treatment remains the principle cause of treatment failure (Kochi 1991). This important barrier to effective treatment control is commonly described at the level of the individual and is often referred to as "non-compliant behaviour". Although individual behaviour and circumstance contribute to non-adherence, it is recognized that poor adherence is ultimately the result of TB control programme failure.

Recognizing the burden of TB and the tremendous effect of non-adherent behaviour on TB control efforts, WHO developed a comprehensive programme aimed primarily at increasing adherence to treatment. The mainstay of this strategy (DOTS, or Directly Observed Treatment, Short-course) is supervising patients taking their anti-tuberculosis drugs, although many other components are required to make this strategy work.

In 2003, 199 countries reported data to the WHO, of which 182 of them expressed commitment to DOTS. It has been estimated that 77% of the world's population lived in areas covered by DOTS by the end of 2003. DOTS programmes notified 3.7 million new and relapsed TB cases, of which 1.8 million were smear-positive. Between 1995 and 2003, 17.1 million TB patients and 8.6 million smear-positive patients were treated in DOTS programmes. The increment in case finding increased by 324,000 between 2002 and 2003. 63% of these additional smear-positive cases were in just two countries: India and China. Among those people who are thought to have developed smear-positive TB in 2003, but were not detected by DOTS programmes, 67% were living in just eight countries: Bangladesh, China, Ethiopia, India, Indonesia, Nigeria, Pakistan, and the Russian Federation (World Health Organization 2004).

1.2 Goals and Objectives

The rapid spread of HIV in sub-Saharan African countries, such as Uganda, has been associated with dramatic increases in the number of TB cases, and with worsening treatment outcomes. TB is a chronic condition and requires long-term treatment. Patient adherence to this treatment is essential. The consequences of non-adherence are severe and may include a delay in curing cases, treatment failure, death, increased relapses of infection, increased rates of transmission, and drug resistance. Directly observed therapy (DOT), the practice of supervising the intake of the anti-tuberculosis medication, is the most effective strategy to ensure compliance. The Kabarole district, in western Uganda, has officially adopted the DOTS strategy in treating TB

cases, yet non-adherence is still identified by the TB programme staff as an important barrier in controlling TB in the district.

It is unclear how to identify the patients who are at risk for poor adherence and how to effectively intervene in these cases. Factors such as socioeconomic status, perception of disease, health seeking behaviour, and access to health care influence both the prevalence and prognosis of TB. Thus, non-adherence is a complex issue and may encompass more broad, social aspects, rather than technical or medical ones. In this study, it was hypothesized that the type and level of family support, with regard to TB treatment, may either directly or indirectly affect the level of adherence to TB treatment. It has been shown in the literature that family support towards TB patients has a positive impact on the health of family members in the counseling and therapeutic process. Studies in Ethiopia (Tekle 2002) and Singapore (Chee 2000) suggest that a lack of family support strongly contributes to non-adherence and may be the most important indicator for predicting non-adherent cases. If this is found to be true in Uganda, it could have important implications for the ongoing attempt to control TB in this country.

Therefore, the primary objective of this study was to determine whether family support is an effective indicator for predicting non-adherent TB cases in Kabarole district, western Uganda. A multi-method approach, integrating complementary quantitative and qualitative techniques, was used to address this objective. More specifically, the study also sought to:

1. Identify differences in levels of family support between adherent and non-adherent TB cases;
2. Assess the knowledge and attitudes towards TB and the DOT approach in families affected by TB;
3. Identify specific family factors that may enhance treatment adherence in TB patients;
4. Identify possible factors and interventions to encourage adherence in those who are at greatest risk to be non-adherent; and
5. Contribute to the improvement of TB control at the district and national levels in Uganda.

CHAPTER 2 – BACKGROUND

2.1 Uganda

Known as the Pearl of Africa, Uganda is a small, landlocked, East African country, covering 236,040 square kilometers. It is a tropical country that is generally rainy with two dry seasons from December to February and from June to August. It borders Kenya and Tanzania on the east, the Democratic Republic of Congo on the west, Sudan on the north, and Rwanda on the south. The capital city is Kampala (population 953 400). Other large cities include Jinja (pop 87,500) and Mbale (pop 72,500).

A map of Africa can be found in Appendix 1, and a map of Uganda can be found in Appendix 2.

Uganda ranks 141st of 162 countries in the Human Development Index, and 125th after adjusting for women. The real GDP per capita per year is $1,167. The adult literacy rate is 77% for males and 56% for females. Other population statistics and indicators are outlined in Table 2.1 (Population Reference Bureau 2003).

Table 2.1 Population Statistics for Uganda, 2003

Population	
Population in thousands, Male	12, 371.6
Population in thousands, Female	12, 408.3
Population growth rate, percent	2.9
Crude birth rate, per 1,000 population	50.4
Crude death rate, per 1,000 population	20.3
Urban population, percent	14.9
Women, 15-49, percent	42.8
Women, 15-49, thousands	5,311.9
Total fertility rate for women 15-49 (lifetime births per woman)	7.10
Contraceptive prevalence rate, women, 15-49, percent	22.8
Maternal mortality ratio per 100,000 live births	1,100
Infant mortality rate per 1,000 live births	106.5
Under age 5 mortality rate, total, per 1,000 live births	159
Under age 5 mortality rate, female, per 1,000 live births	151
Under age 5 mortality rate, male, per 1,000 live births	167
Life expectancy at birth, combined, years	41.9
Life expectancy at birth, female, years	42.5
Life expectancy at birth, male, years	41.4
Population 60 years and over, percent	3-7

2.1.1 History

Arab traders moved inland from the Indian Ocean of East Africa into the interior of Uganda in the 1830s. They found kingdoms in place with well-developed political systems dating back several centuries. These traders were followed by British explorers in search of the source of the Nile River in the 1860s. Protestant missionaries arrived in 1877, followed by Catholic missionaries in 1879.

In 1888, royal charter assigned control of the British "sphere of interest" in East Africa to the Imperial British East Africa Company. This arrangement was strengthened in 1890 by an Anglo-German agreement confirming British dominance over Uganda and Kenya. Owing to the high cost of occupation, the company withdrew in 1893, and its administrative functions were taken over by a British commissioner. In 1894, the Kingdom of Buganda was placed under a British protectorate, and by 1896, the Kingdoms of Bunyoro, Toro, Ankole, and Busoga followed suit. In 1900, the Buganda Agreement was struck, stipulating that the Kabaka (ruler of Buganda) could remain the ruler only if he do so in cooperation with British interests. The entire region currently defined as Uganda was under complete British rule by 1914.

During this time cotton was the economic mainstay of Uganda allowing the country to be economically independent of the British treasury. Coffee production was intensified following World War I and eventually surpassed cotton as the primary crop. To enhance the economic capabilities of the region, a railroad was constructed between Lake Victoria, Kampala, and Kenya.

In 1921, Uganda's first national legislature, the Legislative Council, was established. In its first years, the Council did not allow participation by black Africans. Such representation did not occur until World War II, and by 1954, half of the members of the Council were African. However, the Kingdom of Buganda, which maintained a privileged semi-autonomous status in the colonial protectorate, resented the council because it detracted from Buganda's self-determination. The Kabaka at that time, Mutesa II, was deported for his dissent. This issue of Bagandan autonomy from national structures remains an important issue in Ugandan politics today.

Uganda achieved independence from Britain in October 1962. Following elections in April 1962, Milton Obote, leader of the Uganda People's Congress (UPC), became the first Prime

Minister of independent Uganda. In the following years, Obote and the UPC supported the creation of a strong, centralized state. Opposition groups, particularly those associated with pre-colonial Bantu monarchies, favoured a loose federation and a strong role for tribally based local kingdoms. In February 1966, Obote suspended the constitution, assumed all government powers and removed the ceremonial head of state, the Kabaka, from office. By the following year he had introduced a new constitution that declared Uganda a republic, giving the president greater powers, and abolishing the traditional kingdoms.

Many were dissatisfied with Obote's rule because they did not agree with this centralization of power. This created an ideal situation for the armed forces commander, Idi Amin, to oust the Obote government in a military coup on January 25, 1971. Amin declared himself president, dissolved the parliament, and amended the constitution to give him absolute power. Amin's eight-year rule produced severe economic decline, social disintegration, and massive human rights violations. Since Obote and his supporters were largely from the Acholi and Langi tribes, these tribes were persecuted by Amin. In 1978, the International Commission of Jurists estimated that more than 100,000 Ugandans had been murdered during Amin's reign.

Also in 1978, Amin's troops attempted an invasion of Tanzania but were halted at the border by Tanzanian armed forces. In retaliation for the Ugandan invasion, the Tanzanian army, backed by Ugandan exiles, waged a war of liberation against Amin. On April 11, 1979, Kampala was captured and Amin fled with his remaining forces. Succeeding Amin's removal, the Uganda National Liberation Front (UNLF) formed an interim government with Yusuf Lule as president. This government adopted a ministerial system of administration and created a quasi-parliamentary body known as the National Consultative Commission (NCC). The NCC and the Lule cabinet reflected widely differing political views. By June, 1979, the NCC replaced President Lule with Godfrey Binaisa. He too was removed in May 1980. Thereafter, a military commission chaired by Paulo Muwanga ruled Uganda.

Elections in December 1980, returned the UPC to power under the leadership of President Obote. However, widespread irregularities in the election process led many to question the legitimacy of the election. In early 1981, to protest the results of the election, Yoweri Museveni and his National Resistance Army (NRA), began a guerilla war to oust Obote and the UPC from power. In their efforts to shut down the NRA, Obote's army committed some of the world's worst human right's violations.

Obote ruled until July 27, 1985, when an army brigade composed mostly of Acholi troops and commanded by Lt. Gen. Basilio Olara-Okello, took Kampala and proclaimed military government. Obote fled to exile in Zambia, and the new regime, headed by former Defense Commander General Tito Okello, opened negotiations with the NRA. Massive human rights violations continued as the Okello government murdered civilians and ravaged the countryside to destroy NRA support.

Negotiations between the Okello government and the NRA took place in Nairobi in the fall of 1985, with the Kenyan leadership seeking a cease-fire and a coalition government in Uganda. Although both parties agreed to the cease-fire, fighting continued, and the NRA seized Kampala in January 1986, assumed control of the country, and forced Okello to flee into Sudan. Museveni formed a government with himself as president. He also formed a cabinet comprised of members of several political groups.

In the early years of Museveni's rule, the National Resistance Movement (NRM) was established as an alternative to political parties to aid organization of political expression. Under this system, all Ugandans were assumed to be members of the movement and elections were contested on the basis of the candidates' personal qualities rather than party affiliation. Although the NRM government in Uganda is a *de facto* single party state, political parties are not illegal. They are allowed to maintain headquarters and publish newspapers, but they are not allowed to organize public gatherings or election campaigns. Another important initiative of Museveni's early rule was the establishment of the Resistance Council (RC) system. The RC system was a six-stage pyramid of committees that originated with elections at the lowest level.

The first years of the NRA government saw improved security throughout much of western, central, and eastern Uganda. However, anti-government insurgencies, as well as government efforts to quell the insurgents, contributed to political and economic disruption in northern Uganda. These years also witnessed a rapidly expanding economy and an embrace of neo-liberal economic policies recommended by donor nations, the World Bank, and the International Monetary Fund.

The first national elections under the new government occurred in February 1989, and in a controversial move the NRA extended the NRM's mandate to govern for another five-year

period. In March 1994 national elections were held for a Constituent Assembly (CA), to revise and approve a new constitution for Uganda. These elections were conducted freely and fairly and produced an assembly dominated by supporters of the NRM. The most significant issue addressed was whether or not the new constitution would allow open political competition in a multi-party system, or retain the movement system that severely limits the actions of political parties. The final version of this constitution, promulgated in September 1995, allowed for a national referendum to be held in 2000 to make this decision. This referendum was controversial, with no resolution of the issue.

2.1.2 People

Uganda has a population of 24.8 million and is growing at a rate of 2.9% annually (Table 2.1). Only 12% of the population lives in urban areas. There are 48 distinct ethnic groups in Uganda that follow four main linguistic lines: Bantu, Nilotic, Nilo Hamite, and Sudanic. The largest group, the Buganda, is a Bantu tribe that comprises 13% of the population and is found throughout central Uganda. Other major Bantu groups include the Banyarwanda, Banyankole, Bagisu, Basoga, Bunyoro, and Batoro.

English is the official language for government, education, and commerce. Generally, people speak their native language or dialect first, but will speak English if educated. Those who speak English are highly respected.

Most Ugandans are Christians, although many Sudanic peoples are Islamic. Islam was introduced by Arab traders in the early 19th century, and Christianity came to Uganda in 1875. Most Christian churches also built schools and health centers, so many people converted to Christianity even though they continued indigenous practices. Regardless of religion, nearly all Ugandans have a high level of respect and fear for spirits, demons, and God.

Ugandans cherish their heritage and place great importance on families and clans. They also value economic prosperity, education, and spirituality. In urban areas, there is a trend towards accumulating Western devices such as mobile phones. Appearing wealthy in rural areas is also important; symbols of wealth include land, cattle, multiple wives, and bicycles. Ugandans are polite by nature and admire traits of generosity, friendliness, and a willingness to help others. It is considered immature to express anger or extreme negative emotions in public.

Village families tend to be large, but urban, more affluent families are relatively small. In times of need, Ugandans depend on the extended family for financial support. In addition, it is the responsibility of the eldest (or wealthiest) son to care for aging parents. According to custom, the father protects the family, buys clothing, pays school fees, tills the ground and plants crops. Mothers are responsible for daily care of the house, her husband, and the children. Rural women also harvest crops and sell produce in the local market. Children begin chores as early as three years, helping in the house, fields, and gardens. Legally, children belong to their father, even in divorce.

2.1.3 Politics

Uganda has 48 districts. These districts are divided into counties, sub-counties, parishes, and villages. Elected local councils serve in leadership positions at each level. The constitution allows for a republican form of government with separate executive, legislative and judicial branches. The President is head of state and head of government. The Prime Minister is the head of the cabinet. There are 276 members of parliament elected from the counties. Several seats are reserved for the army, workers, disabled, youth, and women. The voting age is 18.

Uganda's constitution is notable for its protection of the rights of disadvantaged groups, especially women. It endorses affirmative action for women and designates female representation to parliament from each district. Ugandan political institutions are also noted for their emphasis on decentralization of power away from the central government.

Uganda has been criticized for its high level of corruption. The World Bank has charged Uganda as one of the most corrupt countries in the world. It is estimated that approximately $300 million is drained from the country every year from the misuse of funds. Low salaries, poor supervision, and lack of job security are often the reason attributed to such corruption.

On a more positive note, the current government is conducting reforms to enhance education. A Universal Primary Education (UPE) programme was implemented in 1997 and resulted in a doubling of primary school enrollment. The government is also working to eradicate poverty and increase employment throughout the country through their Poverty Action Fund. This fund is intended to improve infrastructure and encourage local manufacturing operations.

Uganda is a member of the United Nations and a founding member of the African Union. It also belongs to the Non-Aligned Movement, the Group of 77, the Organization of the Islamic Conference, the East African Community, Common Market of Southern and Eastern Africa, and Inter-Governmental Authority on Development.

2.1.4 Economy

Agriculture is the mainstay of the economy, employing over 80% of the workforce. Major cash crops include coffee, tea, and cotton. Other crops include soybeans, maize, millet, sorghum, sweet potatoes, cassava, peanuts, and bananas. Livestock include cattle, goats, sheep, and poultry. In addition, Uganda has exploitable deposits of gold, copper, tin, and tungsten, and ample water power sources for producing hydroelectricity. Uganda also produces small quantities of hardwoods, primarily mahogany, for export. The major bodies of water in Uganda are also commercially exploited. Finally, the tourism industry is growing in Uganda.

Uganda's transportation system is not well developed. It has about 28,330 km of roads, only 28% of which are paved. Many of these roads become impassable in the rainy season. The country is also served by 1,240 km of railroad tracks. Ships on Lake Victoria also link Uganda with Kenyan and Tanzanian ports.

The public telephone system reaches the whole country, but offers incomplete service. Mobile phones are relied upon for communication. Several radio stations are run by both the government and private broadcasters. Two major newspapers are widely circulated, including the pro-government *New Vision*, and the independent *Monitor*.

2.1.5 Healthcare in Uganda

Over the past two decades, the Ugandan government has made tremendous progress in restoring the functional capacity of the health sector by re-orienting services to primary health care. However, despite a recent improvement in several health indicators and a rising utilization of the services offered, the government has recognized that important barriers still exist (Ministry of Health 2005). These barriers include a high prevalence of preventable communicable diseases (including TB), a rising incidence of non-communicable disease, a rapidly increasing demand for services due to population growth and the effects of HIV/AIDS, and resource constraints.

To address these barriers, the Ugandan Ministry of Health (MOH) has identified the following strategic objectives (Uganda Ministry of Health 2005):

- To establish policies, guidelines and standards for the delivery of a minimum health care package in the Districts and at the National level;
- To co-ordinate and facilitate all stakeholders in the health sector to achieve the national goals for health;
- To provide sufficient referral and tertiary health care services so that patients who cannot be successfully treated at the District level can receive appropriate medical attention;
- To ensure that sufficient health professional training is undertaken to meet national requirements and regulate the employment of all health professionals to ensure minimum standards of professional practice;
- To co-ordinate research activities in order to support health policy and programme improvements;
- To develop health infrastructure and quality assurance systems that facilitate both District and national planning, and policy implementation, monitoring and evaluation;
- To provide efficient and effective systems and interventions for the aversion of or early identification and control of epidemics.

In addressing these objectives, the government has improved programmes already in place and created other much-needed programmes. They have strengthened vaccination strategies and have achieved excellent coverage rates. They have strengthened relationships with other governmental agencies, such as the Ministry of Water, Lands and Environment, to help control recurrent epidemics of cholera, dysentery, malaria, measles, and meningitis.

The government has made a special commitment to national disease control, in which the priority is the prevention and control of both endemic and epidemic communicable diseases. In addition, the MOH strives to improve capacity for epidemic preparedness and response at both National and District levels, as well as to strengthen programmes for diseases targeted for elimination or eradication (including guinea worm, onchocerciasis, poliomyelitis, neonatal tetanus, measles and leprosy).

2.1.6 Kabarole District

Kabarole district is located in the western part of Uganda, about 320 km south-west of Kampala. The district has a population of 497,422 people of which 239,720 are females. Kabarole has a total area of 1,844.25 sq km of which a large proportion is forest. It borders the districts of Bundibugyo in the west and north, Kasese and Kamwenge in the south, and Kyenjojo in the east. It receives about 1,200 mm rainfall annually. Kabarole is one of the districts in Uganda that depends on agriculture as the main economic activity and source of revenue.

The mission for Kabarole district administration is 'Improving the standard of living of the people through a strategy of efficient delivery of services.' The administration is divided into two counties (Burahya and Bunyangabu), one municipality (Fort Portal), eleven sub-counties, 47 parishes, and 1,120 local councils.

A map of the district can be found in Appendix 3.

History

The district was part of Toro kingdom in western Uganda at the time the country obtained its independence in 1962. But, after traditional monarchies were abolished in 1967, Toro was declared a district and composed of the regions that make up the current Kasese, Bundibugyo and Kabarole districts. In 1974, Toro district was subdivided into three districts that included Semliki, Rwenzori and Toro. However, in 1980 the latter became Kabarole district while the other two became Bundibugyo and Kasese respectively. In 2000, Kabarole was again split into three new administrative blocks, namely Kyenjojo, Kamwenge and Kabarole districts.

The district has a diverse ethnic background with rich cultures. The prominent ethnic groups include the Batooro, Bakiga, Bakonjo and Bamba. The district is multi-lingual and the prominent languages spoken include Rutooro, Rukiga and Runyankole. But this part of the Toro kingdom has a very long and rich history that dates back to 1830. This is the time when the then Prince Olimi Kaboyo carried out a successful secession from the Bunyoro Kitara empire.The kingdom inherited a hard working tradition from Bunyoro-Kitara and prospered very fast under the leadership of Prince Olimi Kaboyo.

Abolition of monarchies in the 1960s greatly undermined the development of the district as it

lost its central authority and the mobilization power of the monarch. The Toro kingdom has its headquarters in Fort Portal, Kabarole district.

District Infrastructure

Kabarole District has substantial road coverage, spanning 718 km of both feeder and access roads. There is still a need to extend the road network to productive rural areas. Hydro-electric power is currently limited to major urban centers, but there are hopes that the government will extend electricity to rural areas through the Rural Electrification Plan.

The major economic activity in Kabarole is agriculture. The crops grown are mostly food crops including sweet potatoes, maize, cassava, soy beans, groundnuts, sunflower, yams, millet and bananas. The district is also among the few districts in Uganda that grows high quality tea.

Health

Kabarole District has three government-funded hospitals (Buhanga, Virika, and Kabarole). All are located within the municipality. They are referral hospitals that serve five districts, including Kasese, Bundibugyo, Kamwenge, Kyenjoj, and Kabarole. The government also supports seventeen health centres, eleven of them at the parish level. Thirteen of the centres are staffed by a qualified medical worker (Kabarole website 2005).

2.2 Tuberculosis in Uganda

According to WHO, Uganda has the seventeenth highest burden (highest number of cases) of TB in the world (Dye 2002). Table 2.2 summarizes the estimated effect of TB in Uganda in 1997 (Dye 1999). Over recent years, the Ugandan government has focused on restoring the functional capacity of the health sector by forming disease control programmes and re-orienting services to a primary health care approach. Despite these efforts, the Ugandan Ministry of Health (MOH) recognizes that their progress is limited by the high prevalence of preventable communicable diseases (such as TB), the HIV/AIDS epidemic (which also increases the burden of TB), and rapid population growth (which produces crowded conditions, allowing TB to flourish). In fact, malaria, acute respiratory infections in children, HIV/AIDS and TB remain the main causes of mortality in Uganda.

Table 2.2 Estimates of the Burden of TB in Africa and Uganda

Rates (per 100,000 persons, per annum, unless otherwise indicated)					
	Incidence	**SS+ Incidence**	**Prevalence**	**SS+ Prevalence**	**Mortality Rate**
Africa	259	108	384	168	35
Uganda	320	128	451	195	34
World	136	60	277	121	32
	Case-fatality Rate (%)	**HIV+ Cases (%)**	**TB/HIV Coinfection**	**Case detection rate (%)**	
Africa	34	32	1194	31	
Uganda	46	50	1532	42	
World	23	8	183	42	
SS+: sputum smear positive					

Latest figures estimate an incidence of 411 cases per 100,000 population per year (based on an estimated Ugandan population of 25,826,698). The incidence of new spear-positive cases is 179 per 100,000 population per year. Prevalence has been estimated at 652 cases per 100,000 population per year. Latest figures also estimate the proportion of adult TB cases who are also infected with HIV to be 21% . Notification rate of TB cases of all forms has been steadily rising, from 129 cases per 100,000 population in 2000 to 162 cases per 100,000 population in 2003 (World Health Organization 2005).

2.2.1 Goals of the National Tuberculosis and Leprosy Programme

As a result of the political upheaval that occurred in Uganda throughout the 1980s, much of the public health system, including all TB control efforts, disintegrated. In 1989, with the help of the German government, TB control services were reinstated in the southwestern region of the country and the National Tuberculosis and Leprosy Control Programme (NTLP) was formed. The aim of the NTLP was to integrate TB control into the overall healthcare system by providing technical support, supervision, and quality assurance to the basic primary health care services in each participating district. This expanded to cover the southeastern and western regions, representing 50% of the population, by 1993. With additional support from the Italian government, services expanded to cover 100% of the population; NTLP achieved full operational coverage in all districts of Uganda in 1995. In 1996, the NTLP reviewed the TB control programme. Although all essential components of TB control were in place, it was

found that the performance of the programme, as measured by key epidemiologic indicators, were inadequate. Poor accessibility to health care services was identified as the primary reason for programme failure. As a result, the decision was made to adopt WHO's DOTS programme.

Community-based DOTS (CB-DOTS) was initially piloted in three districts in western Uganda. Protocol design and preparation of training materials occurred during 1997, and in 1998, community-based DOTS was offered to patients in Kiboga, Rakai, and Apac Districts. A cohort analysis of patients treated with DOTS showed a doubling of the proportion of patients effectively cured (from 33% in 1996 to 61% in 1999), an increased acceptability of the treatment within the communities, and decreased government spending on hospitalizations. In 1999, the government decided to establish this strategy throughout the country. The community-based DOTS programme was officially endorsed by the Ministry of Health, and in 2000, the NTLP received technical support from WHO to continue with the CB-DOTS expansion.

Despite improved treatment success rates under this programme, only 79% of notified cases were registered for treatment, illustrating that there still existed major barriers to the effective control of TB. To address these barriers, the Strategic Plan for Expansion of Community-based Tuberculosis Care was developed as part of the overall Health Sector Strategic Plan 2001-2004. This plan states that the most common cause of treatment failure is non-adherence and default from treatment.

In April 2002, the Ugandan Ministry of Health and the NTLP, in coordination with the WHO Country Office, developed guidelines outlining the integration of TB control and community-based DOTS into the district health systems. The primary goal of this effort was to make effective anti-TB treatment available and easily accessible to all patients. Adopting the WHO objectives for TB control, the NTLP aims for a 70% case detection rate and an 85% treatment success rate.

The NTLP has three operational levels, reflecting the organization of the National Health Service (NHS). There is a central unit at the national level, lead by the Programme Manager, and assisted by nine Zonal TB and Leprosy Supervisors (ZTLS), each responsible for supervising activities in the nine operational zones of the NHS. The management of primary health care is the responsibility of each district and the staff of the health sub-Districts. One member of the district health team is trained as a District TB and Leprosy Supervisor (DTLS).

The DTLS coordinates TB control measures and also provides expertise and training opportunities to the health sub-District coordinators. The final level operates at the health units, located in each sub-county of the district. The health units are responsible for providing care and maintaining contact with the TB patients. This level operates within the public health infrastructure, utilizing existing health care staff at each health centre.

The NTLP trained workers from the district health teams, the district hospitals, and from rural health units. The NTLP provided anti-TB drugs, laboratory equipment and reagents, logistics for training, support and supervision.

2.2.2 Diagnosis and Treatment of Tuberculosis in Uganda

Under the current diagnostic and treatment protocols endorsed by the NTLP, the main method used for TB control is case finding and chemotherapy. Passive case finding, that is, examining those patients who report to health facilities with symptoms, is used and the main method of diagnosis is bacteriological examination of stained sputum smears (Nuwaha 1997). Occasionally, close contacts of a smear-positive patient that have developed symptoms will be screened. Patients presenting to the health unit with any of the following symptoms are screened for TB:

- Persistent cough of three weeks or more in duration;
- Sputum production, which may be blood-stained, shortness of breath, or chest pain; and/or
- Fatigue, loss of appetite and weight loss, a general feeling of illness and fatigue, night sweats and fever.

In order to confirm a diagnosis of tuberculosis, all symptomatic patients must provide sputum samples for microscopic examination. The Ziehl-Neelson method of staining is used in all health units equipped with a microscope and appropriately trained staff. Ideally, each patient provides three sputum samples: the first sample is provided during the initial visit to the health unit, the second is collected at the patient's home upon wakening the following morning, and the final sample is provided during a second follow-up visit to the health unit[1]. Patients who are positive on only a single specimen are referred to a Medical Officer, as are severely sick patients with three negative sputum samples. All patients testing positive, as well as those

[1] The same testing protocol is applied at the end of the second or third month of treatment to confirm sputum conversion, and again at the end of the fifth month of treatment to rule out treatment failure. Sputum examination is done for the last time after completion of the eight-month treatment to obtain bacteriological confirmation that the patient is cured.

patients judged by a Medical Officer to have TB, are registered as TB patients in the district TB register.

Diagnosis and treatment of children poses a special challenge. Only a small proportion of children have smear-positive TB, and many children are unable to produce an adequate sputum sample. Therefore, a diagnoses of TB is made according to the following criteria:

- A history of contact with a case of infectious TB, particularly in the same household;
- Compatible signs and symptoms;
- Failure to thrive and weight loss;
- Non-response to broad-spectrum antibiotic treatment;
- A positive tuberculin skin test (assuming they have not yet received the BCG vaccine); or
- An abnormal chest radiograph showing unilateral lymphadenopathy.

Patients are assigned a treatment regimen based on their disease classification and case category. Disease classifications are based on previous treatments for TB and are summarized in Table 2.3. Case categories are based on the site of infection and bacteriological status and are summarized in Table 2.4.

Table 2.3 Case Definition by Previous Treatment

Disease Classification	Definition
New Case	A patient who has never had treatment for tuberculosis, or who has taken anti-tuberculosis drugs for less than 4 weeks.
Relapse	A patient declared cured but reports back to the health service bacteriologically positive.
Treatment Failure	Smear-positive case who remained, or became again smear-positive, 5 months or later after commencing treatment.
Treatment after Interruption (i.e. Defaulter)	A patient who completed at least one month of treatment and returned after at least 2 months' interruption of treatment.
Transfer In	A TB patient already registered for treatment in one district who transfers to another district for continued treatment.
Chronic Case	A patient who remained smear-sputum positive after completing a directly observed re-treatment regimen.

Table 2.4 Case Definition by Site and Bacteriological Status

Case Category	Definition
Pulmonary Tuberculosis, smear-positive (PTB+)	A patient with at least 2 sputum specimens positive for Acid Fast Bacilli (AFB+) by microscopy; OR A patient with only one sputum specimen AFB+ and radiographic abnormalities consistent with active pulmonary TB; OR A patient with only one sputum specimen AFB+ and a culture positive for *M. tuberculosis.*
Pulmonary Tuberculosis, smear-negative (PTB-)	A patient with symptoms suggestive of TB and at least 2 sputum specimens AFB-, and with radiographic abnormalities consistent with active pulmonary TB (including interstitial or miliar abnormal images); OR Diagnosis based on a positive culture but AFB- specimens; OR A patient with 2 sets, taken at least 2 weeks apart, of at least 2 AFB- sputum specimens, radiographic abnormalities consistent with pulmonary TB and lack of clinical response to one week of broad spectrum antibiotics.
Extra-pulmonary Tuberculosis	A patient with TB of organs other than the lungs. Pleurisy and mediastinal lymphadenopathy are classified as extra-pulmonary TB.

Upon diagnosis, each TB patient is educated about the disease and its treatment. In addition to providing support to the patient, it is hoped that this information will be passed on to other members of the community, encouraging them to seek diagnosis and treatment. Health care workers are expected to discuss the following essential information with each newly diagnosed TB patient:

- What TB is, how it is caused, and how it is spread;
- Any previous treatment for TB the patient may have had;
- The fact that this disease can be cured;
- Treatment of TB;
- The necessity of Directly Observed Treatment;
- The type, amount, and frequency of drugs;
- The importance and required frequency of sputum examination;
- Consequences of irregular or incomplete treatment; and
- Possible side-effects of anti-TB drugs.

Health care workers are also encouraged to impart this information to influential community members within their District to increase community awareness about TB.

Treatment is given to every patient confirmed as having TB, free of charge. Priority for treatment is given to smear-positive patients. Treatment begins with an initial intensive phase, lasting for a minimum of two months until the patient converts to smear-negative status. This ensures that the population of microorganisms is dramatically reduced. Ideally, all patients are routinely admitted to the hospital for this phase. The continuation phase continues at the patient's home for a further six months, and ensures that the patient is cured and will not relapse. During this phase, patients are referred to a health facility nearest to their home to collect continuation drugs on a monthly basis. Adherence is assessed by daily ward attendance for supervised therapy during the first two months and then monthly return to the health centre to collect their drugs in the continuation phase (Stott 1973).

Medications used in Uganda include isoniazid, rifampicin, pyrazinamide, ethambutol and streptomycin. Rifampicin and isoniazid are provided together in a single tablet, as is ethambutol and isoniazid. Streptomycin is available as an injection only. The NTLP provides all districts with these medications. Patients are assigned to a treatment regimen based on their disease classification and category. These regimens are presented in Table 2.5. A further description of dosage schedules for each category can be found in Appendix 4.

Table 2.5 Short-course Chemotherapy Regimens for TB

Category	Initial Phase	Continuation Phase
I. New smear-positive patients, Severe smear-negative patients, Severe extra-pulmonary patients.	2 ERHZ	6 EH
II. Previously treated smear-positive cases, Relapse, Treatment failure, Return to treatment after interruption.	2 SRHZE/ 1 RHZE	5 RHE
III. Children with pulmonary or extra-pulmonary disease.	2 RHZ	4 RH
Note: isoniazid (H), rifampicin (R), pyrazinamide (Z), ethambutol (E), streptomycin (S). The number preceding the letters indicates the duration of treatment, in months.		

2.2.3 Implementing Community-based DOTS in rural Uganda

Implementation of community-based DOTS (CB-DOTS) starts primarily at the health unit level. Ideally, once a patient is diagnosed with TB and returns home for treatment completion, CB-DOTS is initiated. A worker from the local health unit contacts the Parish Development Committee (PDC) or the Local Council II (LC II), requesting them to identify a community volunteer to supervise the patient's treatment. It is recommended that the community volunteer should be a resident of the same village as the patient, should have a reasonable level of literacy (such as a teacher or shop-keeper), should be accepted by the patient, and should understand and accept his/her role as a treatment supervisor. These volunteers are rarely family members. The community volunteer has two main responsibilities: to observe the patient taking the correct daily dose of anti-tuberculosis drugs, and to record the daily intake of drugs on the patient's treatment card. In addition, the volunteer must refer the TB patient to the health unit at two, five, and eight months after starting treatment for follow-up sputum examinations. Finally, if the volunteer recognizes other members of the community displaying signs and symptoms of TB, the volunteer must refer them to the health unit for evaluation.

CHAPTER 3 – LITERATURE REVIEW

3.1 Transmission and Pathogenesis of Tuberculosis

Tuberculosis is caused by the tubercle bacillus, *Mycobacterium tuberculosis*. It is spread primarily through the respiratory tract via droplets produced by coughing, sneezing, speaking, or singing. These activities expel bacilli into the air where they can remain suspended for several hours. The possibility that TB will be transmitted to another person depends on several factors, including the infectiousness of the person with TB (and therefore the number of organisms expelled into the air), the environment (including closeness and frequency of contact), the duration of exposure, the virulence of the organism, and the response of the "recipient".

In developed countries, the following indicators increase the risk of exposure to TB:

- close contacts of people with TB (i.e., those sharing the same household or other enclosed environments);
- foreign-born people, including children, from areas that have a high TB incidence or prevalence (such as Asia, Africa, Latin America, Eastern Europe, Russia);
- residents and employees of high-risk congregate settings (such as correctional facilities);
- health care workers who serve high-risk patients;
- low-income populations with limited access to the health care system;
- high risk racial or ethnic minority populations defined locally as having an increased prevalence of TB (Asians and Pacific Islanders, Hispanics, African Americans, migrant farm workers, Native Americans, the homeless);
- infants, children and adolescents exposed to adults in high-risk categories; and
- substance abusers, especially intravenous drug users or those who use crack cocaine.

Once the bacilli have been transmitted, some travel through the lungs to the alveoli where they are ingested by macrophages. Infection begins when these bacilli begin multiplying. While most of these bacteria are destroyed, a small number survive intracellularly and are released when the macrophage dies. They can then spread through the lymphatic system to regional lymph nodes, and then through the bloodstream to other tissues and organs. Within two to ten weeks after infection, the immune system is usually able to halt the multiplication and render the patient non-infectious. These people still house the bacilli within their bodies, but do not display

symptoms, and are not considered to have active TB disease. This condition is commonly referred to as latent TB infection (LTBI).

In some people, the immune system fails and the bacilli continue to multiply, resulting in the presentation of TB symptoms and progression from TB infection to active TB disease. Approximately 5% of untreated infected people with develop active disease in the first two years following infection. Another 5% will develop active disease later in life (Centers for Disease Control and Prevention 2000). Recent infection is therefore an important risk factor for progression to TB disease.

In addition to recent infection, several other medical conditions will increase the risk of progression from infection to disease. These include (Centers for Disease Control and Prevention 2000):

- HIV infection;
- Substance abuse (particularly drug injection);
- Receiving previous inadequate treatment, or no treatment for a previous infection;
- Diabetes mellitus;
- Silicosis;
- Prolonged corticosteroid therapy or other immunosuppressive therapy;
- Cancer;
- Hematologic and reticuloendothelial disease;
- Renal disease;
- Intestinal bypass or gastrectomy;
- Chronic malabsorption syndromes; and
- Low body weight (10% or more below ideal).

Since TB is transmitted from person-to-person, the risk of becoming infected is strongly associated with the probability of coming into contact with someone who is infectious, the closeness and duration of the contact, and the degree of infectiousness of the case. Factors in the TB patient determining infectiousness, such as severity of disease, presence of cavities, frequency of cough, consistency of sputum and initiation of chemotherapy all contribute to the probability of transmitting infectious microorganisms. In addition, environmental conditions, such as poor ventilation and air quality, as well as situations leading to crowded living

conditions, including poverty and lower socioeconomic status, also increase the probability of transmission of disease. The risk of developing active disease is often related to host factors resulting in a weakening of the immune system. Therefore, HIV infection, older age, poor nutrition, and other concurrent infectious diseases may all contribute early progression of active disease or reactivation of latent disease.

TB disease most commonly affects the lungs, but TB is a systemic disease and can also occur in the pleura, the central nervous system, the lymphatic system, the genitourinary system, and the bones and joints, etc. Considering the mode of transmission, these forms of extrapulmonary TB are very rarely contagious. These forms are more common in immunosuppressed people and young children, and are often accompanied by pulmonary TB.

3.2 Diagnosing Tuberculosis

Multiple strategies exist for diagnosing TB. Procedures used in a given region depend on the local incidence and prevalence of disease, economic feasibility, use of the BCG vaccine, and health care infrastructure available in the region. Diagnostic procedures therefore vary greatly between developed and developing nations.

In many developed countries, targeted testing for TB is undertaken to find people with both TB infection and disease. This means people that at higher risk for exposure to TB, as well as people at higher risk for developing active TB disease once infected, are targeted for screening.

In active tuberculosis, chest radiography is often used to diagnose the disease. However, diagnosis is confirmed by identification of the bacteria on a sputum smear or from the culture of infected sputum. In many developing countries, culture and radiography are unavailable and diagnosis relies primarily on clinical history and the microscopic examination of sputum. The most important epidemiological group includes all smear-positive (infectious) cases because they have the most severe disease, but also because they are the most infectious. These patients are identified primarily through sputum smear microscopy.

3.3 Treatment of Tuberculosis

The basic principles of TB treatment are as follows (Centers for Disease Control and Prevention 2000):

- To provide an adequate duration of therapy to achieve a high probability of cure and at the same time, the most effective therapy available in the shortest amount of time[2];
- To use multiple drugs to which the organisms are known to be susceptible;
- To add more than a single drug to a failing regimen[3]; and
- To ensure adherence to therapy.

Treatment typically utilizes different combinations of anti-tuberculosis drugs. This is important in preventing the emergence of drug resistance, and usually includes isoniazid, rifampicin, pyrazinamide, and either ethambutol or streptomycin. In this combination, isoniazid and rifampicin allow for a shorter course of treatment with high cure rates. Pyrazinamide is a potent drug which allows for an even shorter course of treatment. The fourth drug is added to prevent the emergence of drug resistance when resistance to isoniazid is possible. Once treatment has been initiated, infectiousness of the patient declines rapidly.

Treatment success is defined by sputum smear conversion from positive to negative. The rate of conversion has been shown to be dependent on the initial degree of smear positivity, being slower among patients with a larger bacterial load, as well as in older patients and patients with HIV (Glynn 1998).

Although the fundamentals of treating TB remain the same throughout the world, there are some important differences in treatment strategies in developed and developing countries, largely reflecting the population targeted for diagnosis and treatment. In developing countries with a high burden of tuberculosis, the primary goal is to treat all infectious, smear-positive, pulmonary cases, as well as other cases diagnosed with TB.

In low-prevalence countries, treating latent TB infections as well as active infections, is essential to controlling and eliminating TB. Targeted testing programmes to identify people at

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[2] If treatment is not continued for a sufficient length of time, some bacteria may survive and the patient may become ill and infectious again.

[3] Treatment with a single effective drug can lead to the development of a bacterial population resistant to that drug.

high risk for TB are commonplace. It is recommended that the following people be routinely screened for TB in the United States (Centers for Disease Control and Prevention 2000):

- Patients with HIV;
- Recent contacts of a TB case;
- People with fibrotic changes on a chest radiograph consistent with old TB;
- Patients with organ transplants and other immonosuppressed patients;
- Recent arrivals from high-prevalence countries;
- Injection drug users;
- Residents and employees of high-risk congregate settings;
- Lab and other health care personnel;
- People with clinical conditions that put them at a higher risk; and
- Children exposed to high risk adults.

TB is a social disease no matter which part of the world the patient resides in. With this in mind, an essential component of TB treatment involves understanding how the patients view their illness (Centers for Disease Control and Prevention 2000).

3.4 Control of Tuberculosis

Tuberculosis is a disease that cannot be ignored. History has shown that when public health infrastructures disintegrate, the incidence of TB rises. Every TB case is a potential outbreak. Maintaining strong TB control programmes is essential. The persistence of TB has been due chiefly to the neglect of TB control by governments and poorly managed TB control programmes, and compounded by poverty, population growth and migration, and the HIV epidemic.

Current global efforts to control TB have three distinct, but overlapping, dimensions (World Health Organization 2002):

1. *Humanitarian* (alleviating illness, suffering and death in individuals, focusing on a patient-centered approach to TB control);
2. *Public health* (focusing on proper diagnosis and treatment of TB patients to interrupt transmission patterns); and
3. *Economic* (focusing on reducing the direct and indirect costs to both individuals and society, as well as alleviating poverty and promoting development).

These dimensions illustrate the primary goals of TB control, which are to reduce mortality, morbidity and transmission of the disease, while preventing drug resistance, until it no longer poses a threat to public health. It also aims to reduce human suffering and the social and economic burden families and communities have to bear as a consequence. To achieve this, it is necessary to ensure access to diagnosis and treatment for each TB patient.

TB control programmes can be ineffective for several reasons. Poor treatment outcomes can occur as a result of inadequately trained public health care staff which may lead to faulty selection or dosing of drugs, ineffective record-keeping, and most importantly, failure of the programme to support adherence with absence of follow-up and non-supportive interactions with patients. Biological factors can also contribute to treatment/programme failure. Examples include impaired drug bioavailability related to enteric malabsorption (which may be more common in the presence of advanced HIV infection), adverse effects, drug resistance, re-infection, and inadequate host defenses. The most widespread reason for failed interventions, however, is when the programme does not acknowledge the barriers that make patient adherence difficult, and does not provide mechanisms to overcome these barriers. Limitations in case detection and diagnosis can also lead to unsuccessful program outcomes.

3.5 Directly Observed Therapy

In response to the challenge of patient adherence, WHO recommends Directly Observed Therapy, short course (DOTS) – the practice of supervising the intake of the anti-tuberculosis medication over the six-to-eight month chemotherapy regimen (World Health Organization 1999) This strategy places equal emphasis on the technical, managerial, social, and political dimensions of DOTS. According to WHO, the DOTS approach has five key elements (World Health Organization 1999):

1. *Government and political commitment to sustained TB control activities.* This includes providing human and financial resources, and integrating activities into the public health system. Emphasis is placed on a multi-sectoral and sustainable approach in which TB control activities are considered a component of international, national, and local strategies to alleviate poverty.

2. *Case detection by sputum smear microscopy among symptomatic patients self-reporting to health service.* To be effective, health care services must be available and accessible to all,

especially the poor. In addition, health care workers must be well-informed and practice guidelines must be developed and adhered to. Linking with HIV/AIDS strategies is also important.

3. *Standardized treatment regimen of six to eight months for at least all confirmed sputum smear positive cases, with directly observed treatment for at least the initial two months.* This is particularly important when rifampicin is prescribed.

4. *A regular, uninterrupted supply of all essential anti-TB drugs.* Drugs must be provided free of charge.

5. *A standardized recording and reporting system that allows assessment of treatment results for each patient and of the TB control programme overall.* This will also allow for disease surveillance and monitoring. To be effective, this will require constant communication between peripheral and central health districts.

Implementation of a DOTS programme therefore requires not only adequate resources, but sufficient political will to sustain it. WHO states that 76% of the world's population, and 85% of TB patients, live in countries that have adopted DOTS. However, most of these countries have not implemented the DOTS strategy sufficiently to provide coverage for most cases. In fact, only 27% of global TB cases were treated under DOTS (World Health Organization 2002). In addition, only 42% of all estimated TB cases and 37% of smear-positive cases were reported to WHO in 1997 (Dye 1999).

The DOTS strategy aims for national programmes to detect 70% of smear-positive cases and cure at least 85% of those successfully (World Health Organization 1999) To reach this goal, 85-90% of TB patients must adhere to their treatment regimen. Despite the efforts of DOTS programmes, these goals are difficult to meet. Weak government structures, the HIV epidemic, and especially poor patient adherence to treatment are the main factors held responsible for the limited success of this strategy (Jaramillo 1998).

3.5.1 Implementing DOTS

An important step in implementing a DOTS strategy is detecting as many smear-positive pulmonary cases in the community as possible. Passive case detection is recommended in developing countries for several reasons. Active case finding would be prohibitively expensive in these countries. In addition, it has been shown that four in every five cases have already sought medical attention at the time of detection by mass screening (Dye 1998).

Although case detection is extremely important, it is counter-productive in the absence of high cure rates. If cure rates are not sufficiently high, patients classified as "treatment failures" enter a pattern of long-term transmission to susceptible close contacts. Although treatment of any kind will reduce mortality from TB, short-term, or low quality, treatment regimens could actually increase the rate of transmission, as well as the risk of drug resistance, and ultimately the incidence of TB (Dye 1998). For this reason, it is imperative to educate doctors, community health workers, and other health care professionals, as well as community leaders and teachers, about TB disease and treatment.

3.5.2 Effect of DOTS on the Epidemiology of Tuberculosis

When DOTS is implemented effectively, many key epidemiological indicators of TB will improve, including case detection rates, incidence, prevalence, mortality, and case-fatality rates. Interestingly, it has been postulated that the proportion of deaths prevented by DOTS is greater than the proportion of cases prevented (Dye 1998). This is because treatment that does not completely clear the bacilli can prevent death without eliminating infectiousness, and prevalence decreases sooner than incidence (and prevalence is more directly linked to mortality than incidence) (Dye 1998).

See Appendix 5 for a table summarizing key indicators for TB control.

3.6 Adherence to Tuberculosis Treatment

Poor patient adherence has often been correlated with economic or logistical factors, including socioeconomic status (such as level of education and employment status), disease classification (smear positive, smear negative, or extrapulmonary), active alcohol or drug abuse, side effects of the medication, or access and distance to health units. However, the role that these factors play in non-adherent behaviour has not been consistent across studies. It has been suggested that

more personal factors encompassing patient knowledge of TB, their attitudes toward illness and the social stigma attached to the disease may be more reliable predictors of non-adherence.

The social and psychological factors thought to influence adherence are well documented. Knowledge and understanding of the disease; the patient-provider relationship; social isolation and social support, including the effect of the family; and factors associated with the illness and the treatment including the duration and the complexity of the treatment regimen, all contribute to the willingness of the patient to adhere to treatment (Cameron 1996).

Adherence to treatment varies between countries, and over time, largely due to differences in TB control programme administration. Adherence rates range from 92% in Uganda (Rakai district) (Nuwaha 1999), to 67.8% in Malaysia (Liam 1999), to 44% in Pakistan (Sloan 1981), to only 18% in Ethiopia (Demissie 1994).

Adherence is determined by a wide range of factors related to the treatment course, the health care system, and the patient (Liefooghe 1995). However, in looking for reasons for non-adherence, the literature is clear. At least one-third of all patients, unpredictable by age, gender, race, ethnic background, income, education, social status, occupation, or symptoms of TB, will fail to adhere to their treatment regimen (Sbarbaro 1998, Liam 1999, Tekle 2002, Chee 2000, Nuwaha 1999a, Nuwaha 1996b, Peltzer 2002).

Factors relating to adherence are likely to vary among different cultural cohorts, but certain reasons are consistently cited in the literature as being important. Some of these factors include: decreased motivation to continue treatment upon improvement of symptoms; inaccessibility of health services; family and social factors; and ineffective communication between health care workers and patients (Getahun 2000). Further social and psychological factors include: knowledge and understanding of the disease; patient satisfaction with the treatment and the care they receive; social isolation and social support; health beliefs and attitudes; and TB-related factors, including the duration and complexity of the treatment regimen (Cameron 1996).

3.6.1 Knowledge of TB

Knowledge of TB likely reflects the culture of the population, encompassing both medical information passed to the population through health care workers, community leaders, radio, and other media, as well as traditional, local ideas about the case, transmission, and treatment of TB. Health care workers often have a very different understanding of disease than do the people they treat. Misunderstanding between patient and provider can lead to unsuccessful treatment outcomes. For this reason, it is important to educate not only the population about the medical aspects of the disease, but also the health care professionals about the subjective beliefs of the population.

3.6.2 Attitude Towards TB

Stigma can be a tremendous obstacle to effective TB control, especially if it contributes to non-diagnosis and non-adherence. Stigma can result in a rejection of both diagnosis and treatment of TB, exacerbating the administrative and logistical difficulties of TB control (Getahun 2000). In addition, when a community holds a strong negative view of TB, this can result in a negative effect on social relations and the moral identity of those infected. It is important to determine the nature and extent of stigma in Uganda so that effective strategies to combat it can be developed. In determining where this stigma originates from, it is helpful to look at the semantics of TB in the community: how this disease is and is not spoken about, by whom, in what context, and for what reasons.

3.6.3 Family Support

Very little research has been done to determine the role of family support in promoting adherence to TB treatment. However, an Ethiopian study found that the risk of defaulting was lower if the patient had family support (Tekle 2002). A Vietnamese study has shown that although there is very little community support, there seems to be support within the family and this has a positive effect the patient's outcome (Johansson 1996). A study in India discovered that adherence was associated with the presence of social or family support (Barnhoorn 1992). A Kenyan study concluded that the family is important in influencing the patient's health-seeking behaviour and in giving social and financial support (Liefooghe 1997).

6.3.4 Gender and TB

In women of reproductive age in developing countries, TB is the third most common cause of morbidity and mortality combined, and kills more women than any other infectious disease, including malaria and AIDS (Murray 1990). Yet, there are 70% more smear-positive male than female TB patients reported to WHO each year (Diwan 1999). Epidemiological research shows that there are gender differences in prevalence of infection, incidence of clinical disease, and mortality due to TB (Holmes 1998).

The experience of TB infection differs between men and women, on a physiological and cultural level. One study found that in addition to having decreased access to diagnostic centers, women were also less likely to undergo a sputum examination when they presented with respiratory symptoms (Begum 2001). As well, some studies have suggested that progression from TB infection to active disease may actually be faster in women in the reproductive age group than in men of the same age (Nsubuga 2002). This could particularly true in areas where women's health is worse then men's (especially in terms of nutrition and HIV). Despite this, mortality due to TB appears to be similar among young men and women (Nsubuga 2002).

Differences in treatment adherence between male and female patients have also been postulated. Reasons for this could be related to issues of access, and include the possibility that women have less financial resources for transport and personal health care than do men (Nsubuga 2002). Other studies have shown that women have increased adherence compared to men (Johansson 1999, Long 1999).

Men and women have been shown to identify different obstacles to adherence. A study in Vietnam found that men were more likely to identify insufficient knowledge and cost of treatment as barriers, while women were more likely to identify social stigma and negative interactions with health care workers as barriers (Johansson 1999). Another study also suggests that this fear of stigmatization had a greater impact on women than men (Hudelson 1996). An Indian study found that while men worried about loss of wages, financial difficulties and reduced capacity for work, women worried about rejection from their husbands, harassment by their in-laws, and reduced chances for marriage (Nair 1997). This study also found that women received less family support than men, expressed in terms of rest-time and workload.

3.7 HIV/AIDS and Tuberculosis Infection

Recent epidemiological estimates of global TB and HIV indicate that 11% of all new TB infections in adults were attributable to HIV infection, and of the 1.9 million deaths from TB, 18% were attributable to HIV (World Health Organization 2002). In addition, TB was identified as the immediate cause of death in 15% of all adult AIDS patients, only 32% of which actually received treatment for TB (WHO 2002). The prevalence of TB/HIV co-infection in adults is estimated to be 0.41%, but reaching greater than 5% in several sub-Saharan African nations (World Health Organization 2002).

HIV/AIDS has been identified as the single most important risk factor for developing active TB disease, in an individual infected with *M. tuberculosis,* particularly in developing countries where the prevalence of both diseases is high. Studies have suggested that the risk for developing TB is 7 to 10% each year for people co-infected (compared to only 10% over a lifetime in immunocompetent patients) (World Health Organization 2000). It is also widely recognized that TB is the leading cause of morbidity and mortality in HIV-infected individuals.

Until recently, the WHO strategy for TB in high HIV prevalence populations consisted of a "dual strategy for a dual epidemic" (WHO 2002). This comprised a strategy for HIV/AIDS care, which often neglects TB, and the DOTS strategy, which often neglects HIV/AIDS care. HIV infection fuels the TB epidemic in several ways. This exemplifies the importance of integrating strategies for HIV prevention into TB control. Although effective case finding and cure through the DOTS strategy interrupts disease transmission, this is not sufficient to counteract the impact of HIV. Additional interventions aimed at decreasing HIV transmission, such as promoting condom use and treating other sexually transmitted disease, as well as offering anti-retroviral therapy and preventative antibiotic prophylaxis to HIV patients, should be encouraged in TB control programmes (World Health Organization 2002). However, TB control programmes must first improve their core TB control functions.

3.8 Drug-resistant Tuberculosis

There are two types of resistance to anti-tuberculosis drugs (World Health Organization 2000):

1. Primary resistance develops when an individual is initially infected with resistant organisms;
2. Secondary resistance, or acquired resistance, develops during TB therapy. Resistance can occur when a patient is treated with an inadequate regimen, or when a patient does not complete their prescribed regimen.

Risk factors for drug resistance include: a history of treatment for TB, contact with people known to have drug-resistant TB, people either residing in, or born in, an area of high MDRTB prevalence, or patients with sputum smears remaining positive after two months of continuous treatment.

CHAPTER 4 – METHODS

Both qualitative and quantitative techniques were employed in this retrospective case-control study. Quantitative methods included the administration of a questionnaire to primary caregivers or family members of TB patients that were identified as being either adherent or non-adherent in the district TB registry. These questionnaires assessed the knowledge, attitudes, and supportive behaviours of the respondents. Qualitative methods included in-depth interviews with health care workers, DOTS volunteers, TB patients, and their families. The interviews were designed primarily to allow individuals to freely discuss their concerns with TB in Uganda.

4.1 Conceptual Framework

This study was conducted within a "determinants of health" conceptual framework. In this framework, it is recognized that disease is a complex phenomenon, an interaction between biological, social, behavioural, and environmental factors. Developing effective control and prevention strategies requires not only knowledge of the causes of disease, which can be very broad and far-reaching, but the underlying social and environmental conditions that allow the transmission of that disease to continue throughout the community. In addition to recognizing how factors such as nutritional status, living conditions, income, and level of education contribute to disease burden, the attitudes and beliefs, family and social support systems, community cohesiveness, public policy, social justice, and cultural environment must also be acknowledged.

4.2 Objectives

It was anticipated that the level and type of family support plays an important role in promoting adherence to DOTS treatment for TB, and that non-adherence to such therapy correlates with lower levels of family/spousal support. Low levels of family/support were thought to be evident through the attitudes of the family towards TB and the negative stigmatization they associate with this disease. It could also be illustrated through a lack of knowledge about the disease itself and also the DOTS approach, including the duration of the treatment. Finally, low levels of family/spousal support could also be noticed as a lack of support and encouragement provided to the TB patient and family by the TB programme.

Ultimately, by demonstrating the role of family support in adherence to TB treatment, it was anticipated that this study would aid in programme development by improving TB control at both the district and national level. Involving family members in the care plan for TB patients and educating family members on the importance of treating TB may be an important step in controlling the transmission of TB in Uganda. Currently, this is not standard practice in Kabarole, Kamwenge, and Kyenjojo districts.

4.3 Setting

The study took place in Kabarole district, western Uganda. This was an ideal location because of the longstanding professional relationship between the Basic Health Services (BHS) Project and the researcher's thesis supervisor, Dr Walter Kipp, who served as the Team Leader of BHS from 1988 to 1994. Dr Kipp had previously facilitated several student projects in Fort Portal. As a result, staff of Basic Health Services (BHS) were accustomed to working with Canadian students, making it an ideal location for this project.

Staff at BHS were contacted one year prior to project implementation. The staff were asked to identify a list of potential research questions they felt were important. Approval for this study was sought from BHS, as well as a commitment to provide technical and logistic support. This allowed local involvement and ownership of this study right from the start.

4.4 Research Team

4.4.1 Stakeholders

The entire fieldwork component of this study was directed and supervised by Mr. Tom Rubaale, Basic Health Services Team Leader; Dr. Geoffrey Kabagambe, Director of District Health Services of Kabarole district; and Peter Rwakilembe, District TB and Leprosy Supervisor, Basic Health Services. These individuals were either directly or indirectly involved with initial topic identification, study design, sampling decisions, selection of research assistants, the fieldwork component, and/or interpretation of results. They also provided invaluable cultural and linguistic support. Other important stakeholders included the Basic Health Services project staff, the District Health Management Team, the Ugandan Ministry of Health, and the National Tuberculosis and Leprosy Programme. Stakeholders included private health care facilities, which care for significant numbers of TB patients. This study will ultimately benefit the impoverished populations of Uganda, who carry a significant burden of disease and suffer a lower quality of life because of TB.

4.4.2 The Research Team in the Field

Upon arrival in Kampala, Uganda, the proposal for this project was presented to Professor Konde-Lule at the Public Health Institute, Makerere University. He provided advice regarding the content of the questionnaire, methods, and proper protocol for obtaining approval at the national, district, and village level. In addition, Dr Kabagambe and Peter Rwakilembe of the Basic Health Sciences in Fort Portal assisted in study design and logistics.

Meetings were held with the local TB staff to discuss their impressions of this project and potential obstacles we could encounter in the field. TB staff were also given a preliminary copy of the questionnaire and were encouraged to suggest changes to make the questions more culturally appropriate and relevant to the unique experience of TB patients and their families in Kabarole district. To further encourage ownership by local health staff, several questions that were not particularly relevant to the study question were included in the survey to ensure some of questions considered important by the staff were answered.

The research team in the field consisted of the author as primary researcher, the District TB and Leprosy Supervisor (DTLS), and two local research assistants. These research assistants were recruited specifically for this study by the Kabarole Research and Resource Centre. Both assistants were male and recent graduates of Makerere University (Education majors). They were natives of Fort Portal and knew the district well. Transportation into the field was coordinated by the DTLS and Team Leader of the Basic Health Services. A vehicle and a driver were also supplied by BHS.

4.5 Quantitative Component

With help from the TB Programme Coordinator, all non-adherent TB patients were identified from the District TB Registry. A matching number of adherent TB patients were identified from the same villages and sub-districts. With the help of local village guides and chairmen, the TB patients and their families were asked to participate in the study. Participants were given 2,000 Ugandan shillings ($1.40 CDN) for taking the time to complete the questionnaire (approximately 45 minutes). The questionnaire was administered in Rutoroo by the local research assistants.

The questionnaire (see Appendix 8) contained both closed-ended and open-ended questions and was aimed at determining the level of knowledge participants have about TB, their attitude

towards it, and what they do to support the treatment of the infected members of their family. Most questions were open-ended to allow participants to freely discuss their opinions on the topic. They were also given the opportunity to ask questions at the end of the questionnaire. Upon completion of all questionnaires, open-ended questions were coded and grouped to facilitate quantitative analysis.

4.5.1 Questionnaire Development

With input from TB health care staff and the research assistants, a working copy of the questionnaire was developed. It was agreed that the DTLS would translate the questionnaire into Rutoroo, the language spoken in Kabarole district. The DTLS had very good technical knowledge of TB. He also understood the type and quality of data each question was aimed at extracting from the participants. The DTLS also translated the information letter and consent form.

Once the questionnaire was translated, a local university student was employed to translate the Rutoroo version back into English to ensure proper translation. Several of the questions resulted in inadequate back translation. The DTLS and the primary researcher met to discuss the discrepancies, and then a final version of the questionnaire was agreed upon. The information letter and consent form were also back-translated, with no discrepancies.

The research assistants then received training on how to describe the study, obtain informed consent, and administer the questionnaire. They were instructed to read each question exactly how it was written on the page (in Rutoroo) and write down the participants' responses, word for word. Each question was explained to them in detail to ensure that they had a good understanding of what each question meant. If they felt that participants were misunderstanding the question, they were given the freedom to further explain the question to the participant. They practiced administering the questionnaire on staff at the Kabarole Research and Resource Centre.

Once the research assistants were comfortable with the questionnaire, each assistant pre-tested the questionnaire on five participants (three adherent and two non-adherent). To establish face and content validity, discussions were held to ensure the intended meanings of questions were understood by the participants, to identify problem questions, and to examine any difficulties the assistants had. All problems were addressed, with no need for further change to the

questionnaire. The research team felt the questionnaire was adequately developed after these ten pre-tests, and approval was given to begin data collection.

4.5.2 Study Site and Sample Population

Participants were identified from the rural population in Kabarole district via records kept by the DTLS in Fort Portal, Uganda. The study population consisted of caregivers of both current and previous tuberculosis patients. These caregivers were largely family members (spouses, children, siblings, parents, or extended family) but also included close family friends, house workers, and village leaders. Since no caregivers or DOTS supervisors are recorded in the TB registries, each household was asked to identify the person who was closely involved with the TB patient in the family. The TB patients were classified as either adherent (i.e, controls) or non-adherent (i.e., cases) to their TB treatment in the TB treatment registry found at the health unit where the TB patient was diagnosed. In the initial proposal, non-adherence was defined as treatment interruption for a cumulative period of four weeks or longer. However, the TB registries in Uganda define non-adherence as three consecutive months without treatment, so the protocol for participant selection was modified to reflect this.

The study population consisted of 207 families affected by TB; half of these families were to have an adherent TB patient, the other half were to have had non-adherent TB patients. Initially, non-adherent patients were to be identified via systematic random selection from all registered TB patients in Kabarole district. These patients were to have been matched by geographical location and race/ethnic group to adherent patients, who would also be identified through the registries. However, due to inconsistent record-keeping in the registries, transportation difficulties, and a less-than-expected number of registered TB patients, all non-adherent TB patients identified in the registries were asked to participate. Again, due to the problems mentioned above, matching was very difficult. Instead, for each village where non-adherent patients were identified, an equal number of adherent patients' families were approached, resulting in frequency matching.

To minimize the chances of bias, all research assistants, interviewers and participants were blinded as to which group the TB patients belonged to (adherent or non-adherent). Although non-adherence would likely become evident during the questionnaire administration, this blinding was attempted to prevent differential treatment of the respondents from the onset.

4.5.3 Sample Size and Power Considerations

With a sample size of 200 (100 participants in each group), odds ratios of 2.0 and larger will be detectable with 80% power and 95% confidence intervals (2-sided). Although comparisons may not reach statistical significance, validation was sought through in-depth interviews.

4.5.4 Questionnaire Administration

Questionnaires were administered by the research assistants to all families giving their consent to participate in the study. The primary researcher was present during most interviews. Each meeting was attempted to be done in a private location. However this was not always possible. The questionnaire included 64 questions that were composed of yes-no, forced choice, and open-ended questions. Each questionnaire lasted forty-five minutes, on average. Participants were given the opportunity to ask questions at the end of the questionnaire. Very few participants had any comments or questions.

Participant names were never recorded. Completed questionnaires were assigned sequential numbers by the researcher and recorded in a confidential notebook along with data relating to their diagnosis obtained from the TB register.

At the end of each questionnaire, respondents were thanked for their participation and given a small amount of money as partial compensation for their time. In addition, local health workers, LC-1s, and other community leaders were often employed as guides, assisting in locating TB patients. These individuals were given 5,000 Uganda shillings (about CAN $1.40) per day for their time.

4.5.5 Inclusion and Exclusion Criteria

The inclusion criteria for identifying TB patients, and their families, for this study were as follows:

1. Patients who began their treatment in Kabarole district;
2. Patients who had enough contact details recorded in the district TB register to ensure that researchers could contact them;
3. Patients who were registered between 2001 and 2003; and
4. Patients who were at least sixteen years of age at the start of treatment.

In the initial protocol, patients who had died were to have been excluded. However, this proved to be difficult, since this information was very rarely recorded in the register. If patients had died, this usually was determined while administering the questionnaires. Upon discussion with other research team members in Uganda, it was decided that including patients who died before completing their treatment could, in fact, provide useful information. Hence, deceased TB patients were included in the study.

4.5.6 Methods and Analysis

Data entry was the sole responsibility of the researcher and was completed before leaving the study setting. Answers to open-ended questions were categorized, coded, and entered into the Statistical Package for the Social Sciences (SPSS) database, as well as undergoing qualitative content and thematic analysis. Hard copies of the questionnaire are currently stored in a locked cabinet at the BHS project office. All survey data were analyzed using the SPSS version 11.5 for Windows.

Univariate, bivariate, and multivariate methods were used. Descriptive and comparative analysis of variables was achieved through chi-squared analyses. In addition, each participant was scored on their knowledge of TB, their attitude towards TB, and the support they provided to the patient in their family. Crosstabulations and chi-squared testing were conducted to compare demographic variable between adherent and non-adherent groups, as well as between patients who died before completing their treatment and patients who did not die. In addition, logistic regression was conducted with default status as the dependent variable to explore the same comparisons, after controlling for all other variables under question.

Relevant questions from the survey were categorized as a Knowledge, Attitude, or Support question. Possible answers for each of these questions were then coded and scored according to their appropriateness. The higher score was given to the most positive answer (i.e., to indicate higher knowledge, a more positive attitude, or a more supportive behaviour). Scores for each question in each category were summed to give each participant a Knowledge, Attitude, and Support score.

These scores were then used to test for differences between study groups. The Pearson correlation coefficient was used to assess the relationship between age and scores. For other variables, the Independent Samples t-test was used. Some of these variables proved to be non-

normally distributed; in these cases, the non-parametric Kruskal-Wallis test was used to examine difference in scores. All scores are expressed as mean ± SD. A p-value of less than 0.05 indicated statistical significance.

Multivariate analysis was conducted to explore the relationship between Total Score and various TB patient and study participant characteristics. Linear regression was used to form a full model containing all of these variables, using Total Score as the dependent variable. Reduced models containing all but the variable under study, were also formed. Each reduced model was compared to the full model using the following equation:

$$F = \frac{\text{Regression Sum of Squares (full model)} - \text{Regression Sum of Squares (reduced model)}/1}{\text{Mean Square Residual (full model)}}$$

The resulting F statistic explains the degree to which the variable under study explains Total Score, after controlling for all of the other variables. The F statistic has an F distribution with degrees of freedom 1 (number of variables in the full model – number of variables in the reduced model) and 190 (Total sample size – number of variables in full model – 1).

4.6 Qualitative Component

Initially, in-depth interviews and focus groups of randomly selected study participants were to be conducted. However, because of time limitations and transportation difficulties, this could not be conducted as planned. Eight in-depth interviews were carried out and confirmed the common answers given in the questionnaire.

As the fieldwork progressed, a gap between the written protocol for TB control and reality became evident. There are very specific procedures outlined in the DOTS procedure manual. The staff involved in TB control insisted, at the beginning of the study, that these were the procedures followed. However, after spending time in the community, it was obvious that many of these procedures were not being followed. As a result, the research team felt it would be beneficial to interview some key informants in the TB control programme. These interviewees included the TB Programme Coordinator, a DOTS volunteer, and a community health worker involved in delivering TB drugs to the villages. Since these interviewees all spoke English fluently, the interviews were conducted by the researcher. All interviews were tape-recorded and transcribed by the researcher before leaving the study site. This information was invaluable

in interpreting the results of this study within the true context of the healthcare system in rural western Uganda.

In addition, several interviews were conducted with TB patients and their families. The purpose of these interviews was to encourage participants to discuss their experience of TB within the family. None of these participants spoke English, so interviews were done by the research assistants in Rutoroo. The research assistants were briefed on what type of information these interviews were intended to gather, and were given a list of probing questions to use to facilitate the discussion. After the first two interviews, it was evident that the research assistants did not understand the purpose of these interviews, as they were simply re-asking many of the questions from the questionnaire, rather than encouraging discussion. For the remaining interviews, the researcher accompanied both research assistants to the interviews. One research assistant guided the discussion, in Rutoroo, while the second researcher wrote notes from the discussion, in English. In this way, the researcher could follow the interview and provide the research assistants with further probing questions. All interviews were tape-recorded, and then transcribed and translated by the research assistants. Unfortunately, this system appeared to make participants quite uncomfortable, and so very little useful data was collected.

4.7 Ethics Considerations

Ethics approval was granted from the Health Research Ethics Board (B: Health Research) at the University of Alberta and the National Council for Science and Technology in Uganda. In addition, approval was granted from the Director of District Health Services in Kabarole District. Upon arrival at each health unit, the study was described to the health worker responsible for maintaining the local TB register, and permission was sought to view these registers. Finally, for each sub-county visited, the researcher, accompanied by the District TB Supervisor, met with the Local Council members for the area to explain the purpose of the project and request approval and support for the fieldwork activities. No problems were encountered in this process.

The study team was instructed to maintain cultural sensitivity and to respect the resistance or concerns of the participants. An information sheet outlining the study's purpose and scope was given to each of the study participants to ensure informed consent as well as to build trust and mutual respect (Appendix 6). The information sheet also stated the policy on confidentiality and stated that participants were free to leave the study at any time without repercussions. However,

because there was a concern that many of the participants would be unable to read or write, the research assistants verbally described the content of the information letter, stressing the confidentiality of the answers provided, as well as the benefits and risks associated with the study. Counseling was offered to participants if they experienced any stress related to the interviews and the study. Participants were asked to sign a copy of the information letter to ensure their understanding of the content, as well as the consent form. In those cases where participants were unable to write, their thumbprint was stamped on the page to indicate consent. People who were unwilling to participate were recorded and were asked to provide a reason for their non-participation.

4.8 Dissemination of Initial Study Results

Because members of the Basic Health Services team were involved in this study, they had direct access to the primary data as the data became available. Following data collection and preliminary analyses, a presentation was given to the Fort Portal district health staff, the Basic Health Services team, and other interested individuals. Feedback was sought to better ensure the appropriateness of the approach taken to the analysis and presentation of the findings. In addition, the research team, including the research assistants and translators, were briefed on the study, and were encouraged to disseminate the results throughout the community.

CHAPTER 5 - QUANTITATIVE RESULTS

5.1 Characteristics of Tuberculosis Patients in Kabarole District

The 2001 TB/Leprosy Control Programme Annual Report, January – December 2001 (unpublished), prepared by the District Tuberculosis and Leprosy Coordinator, describes the characteristics of patients in the Kabarole district of western Uganda. In this year, 886 new cases of TB were reported to the national TB/Leprosy programme. Of all cases reported to the NTLP, 303 (34.2%) were smear positive new cases. Of these, 61% were male and 88.4% were between the ages of 15 and 54 years. A summary of all reported cases appears in Table 5.1 and the age and sex distribution of new smear-positive pulmonary cases appears in Table 5.2.

Table 5.1 Total categorized TB patients reported to NTLP in 2001

Category	N (%)
Smear positive new cases	303 (34.2)
Smear positive relapses	42 (4.7)
Smear negative new cases	414 (46.7)
Smear negative relapses/defaulters	80 (9.0)
Extrapulmonary	10 (1.1)
Other retreatment	37 (4.2)
Total	886 (99.9%)

Table 5.2 Age and sex distribution of new smear-positive pulmonary cases, Kabarole District, 2001

Age Group	1-14	15-24	25-34	35-44	45-54	55-64	65+	TOTAL
Male	3	28	63	45	26	13	6	184 (60.7)
Female	6	24	50	20	12	4	3	119 (39.3)
TOTAL (%)	9 (3)	52 (17.2)	113 (37.3)	65 (21.4)	38 (12.5)	17 (5.6)	9 (3.0)	303 (100)

5.2 Interviews with Family Members of Registered TB Patients

Patients were selected from the district TB registry on the basis of default status. Of the 207 patients selected, 106 (51.2%) were identified as "defaulters", 78 (37.7%) completed their treatment, and 19 (9.2%) died before completing their full course of treatment. The status of the remaining 4 (1.9%) participants was not clear, and were excluded from the analysis.

5.2.1 Study Population

209 families affected by TB were approached for participation in the study. Two people refused participation: one claimed the TB patient in her family was not suffering from TB, and another refused without stating a reason. Questionnaires (see Appendix 8) were administered to 207 family members of TB patients in Kabarole District of western Uganda in October, November, and December, 2003, 106 being from family members of non-adherent patients.

5.2.2 Socio-Demographic Characteristics of Study Participants

Characteristics of study participants are summarized in Table 5.3. All study participants were from small, rural villages within Kabarole District. Of the study participants, 121 (58.5%) were female. The majority of participants were born in one of the districts under study (89.8%). The average age of the participants was 40 years (SD ± 17.30), ranging from 15 to 89 years. 73.4% of participants had either Primary or Secondary education, with only five (2.4%) attending a higher level institution[4].

The majority of participating families lived in houses with metal roofs (89.9%) and earthen floors (84.5%), and reported either relying on bicycles for transportation (33.3%) or had no available method of transportation (55.1%); 85% of households had a radio. Study participants were primarily farmers/cultivators (40.6%), shop keepers (6.8%), or traders (4.8%). The remaining participants' source of income included casual labor, tea plantation work, animal husbandry, self-employment, money from family members, or none. Participants shared their houses with an average of six (SD ± 2.5, range 1-15) other people, including an average of three (SD ± 1.9, range 0-9) children. Almost half (48.3%) of participants reported living with children under the age of five years. The majority of compounds housed only one married woman (67.1%).

Study participants were primarily a spouse (22.7%), sibling (26.1%), or parent (26.1%) of the TB patient. The remaining participants were either a child of the TB patient (5.8%), an extended family member (15.9%), or were unrelated to the TB patient (3.4%).

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[4] Primary (P) education includes P1 to P7 and is roughly equivalent to elementary (grades 1 to 6) school in Canada. Secondary (S) education includes S1 to S6, which is roughly equivalent to junior high and high school in Canada. Higher level education included attendance at teachers' college, a business school, or a technical institute.

Table 5.3 Characteristics of study participants

Characteristic	Adherent N(%)	Non-adherent N(%)	Died N (%)	Total N (%)%
Gender				
Male	32 (38.1)	49 (58.3)	3 (3.6)	84 (41.4)
Female	46 (38.7)	57 (47.9)	16 (13.4)	119 (58.6)
Relation to TB Patient				
Spouse	14 (30.4)	28 (60.9)	4 (8.7)	46 (22.5)
Sibling	17 (32.7)	30 (57.7)	5 (9.6)	52 (25.5)
Child	6 (50)	6 (50)	0	12 (5.9)
Parent	20 (36.4)	28 (50.9)	7 (12.7)	55 (27.0)
Extended family	18 (54.5)	12 (36.4)	3 (9.0)	33 (16.2)
Other	3 (50)	3 (50)	0	6 (2.9)
Highest Level of Education				
Primary school	46 (39.3)	60 (51.3)	11 (9.4)	117 (13.0)
Secondary school	11 (40.7)	14 (51.9)	2 (7.4)	27 (58.0)
Institution	3 (60.0)	2 (40.0)	0	5 (2.4)
None	29 (53.7)	19 (35.2)	6 (11.1)	54 (26.6)
District of Birth				
Kabarole	69 (41.3)	90 (53.9)	8 (4.8)	167 (86.5)
Kyenjojo	0	3 (100)	0	3 (1.6)
Kamwenge	1 (50.0)	1 (50.0)	0	2 (1.0)
Other	6 (31.6)	12 (63.2)	1 (5.3)	19 (9.8)
Unsure	2 (100)	0	0	2 (1.0)
Mode of Transportation				
None	51 (45.1)	48 (42.5)	14 (12.4)	113 (55.1)
Car	3 (37.5)	5 (62.5)	0	8 (3.9)
Motorcycle	4 (26.7)	11 (73.3)	0	15 (7.7)
Bicycle	20 (29.9)	42 (62.7)	5 (7.5)	67 (33.3)

Characteristic	Adherent N(%)	Non-adherent N(%)	Died N (%)	Total N (%)%
Roof				
Metal	70 (38.3)	95 (51.9)	18 (9.8)	183 (89.8)
Thatched	8 (44.4)	9 (50.0)	1 (5.6)	18 (9.2)
Unknown	0	2 (100)	0	2 (1.0)
Floor				
Cemented	17 (60.7)	10 (35.7)	1 (3.6)	28 (14.0)
Earthen	61 (34.9)	93 (53.1)	18 (10.3)	175 (84.5)
Unknown	0	3 (100)	0	3 (1.4)
Primary Source of Income				
None	12 (30)	21 (52.5)	7 (17.5)	40 (19.3)
Civil servant	1 (20.0)	4 (80.0)	0	5 (2.4)
Trade (mechanic, plumber, builder)	1 (33.3)	2 (66.7)	0	3 (1.4)
Self-employed	6 (66.7)	2 (22.2)	1 (11.1)	9 (4.3)
Trading	5 (50.0)	4 (40.0)	1 (10.0)	10 (4.8)
Money from family	2 (50.0)	2 (50.0)	0	4 (1.9)
Tea plantation	5 (71.4)	1 (14.3)	1 (14.3)	7 (3.4)
Shop keeping	8 (57.1)	6 (42.9)	0	14 (6.8)
Casual labor	2 (20.0)	8 (80.0)	0	10 (4.8)
Animal husbandry/milk	3 (33.3)	5 (55.6)	1 (11.1)	9 (4.3)
Farming food crops	29 (34.5)	46 (54.8)	9 (10.7)	84 (40.6)
Other	5 (41.7)	6 (50.0)	1 (8.3)	12 (5.8)
Children Under 5 in Household				
Yes	32 (32.7)	56 (57.1)	10 (10.2)	98 (48.3)
No	35 (43.8)	39 (48.8)	6 (7.5)	80 (39.1)
Unsure	11 (44.0)	11 (44.0)	3 (12.0)	25 (12.6)

Results of the univariate and multivariate analysis for study participant characteristics are summarized in Table 5.4 (Adherent versus Non-adherent groups) and Table 5.5 (Died versus Did Not Die groups)

There was a significant difference between respondents related to patients who were non-adherent and patients who were adherent. Respondents who were immediate family members were less likely to have a non-adherent TB patient in the family ($p = 0.062$, OR = 0.483 (0.233, 1.001).

There was a significant difference in the gender of the study participants. Male respondents were significantly more likely to have the TB patient in their family die ($p = 0.026$, OR = 4.216 (1.188, 14.956)).

Families with an earthen floor had 2.592 (1.113, 6.035) the odds of having a non-adherent TB patient than families with a cement floor. This was not a significant association in the multivariate analysis.

There were no significant differences between the three groups in all other socio-demographic characteristics ($p > 0.05$).

Table 5.4 Study Participant Characteristics – Adherent vs Non-Adherent Groups

Variable	Univariate Analysis		Multivariate Analysis	
	p-value	OR (95% CI)	p-value	OR (95% CI)
Gender	0.548	1.236 (0.684, 2.232)	0.159	1.645 (0.823, 3.291)
Relationship to TB Patient	0.062	0.483 (0.233, 1.001)	0.057	0.455 (0.202, 1.024)
Age	0.644	1.166 (0.636, 2.137)	0.587	1.206 (0.613, 2.374)
Level of Education	0735	0.855 (0.437, 1.672)	0.684	0.849 (0.386, 0.867)
Children under 5 years	0.136	0.621 (0.344, 1.121)	0.094	0.560 (0.284, 1.104)
Radio	1.000	0.924 (0.403, 2.118)	0.894	1.065 (0.423, 2.682)
Roof	0.799	0.829 (0.305, 2.256)	0.647	0.786 (0.281, 2.200)
Floor	0.034	2.592 (1.113, 60.35)	0.070	2.339 (0.934, 5.837)
Source of Income	0.368	0.739 (0.408, 1.363)	0.197	0.645 (0.331, 1.253)

Table 5.5 Study Participant Characteristics – Died Before Completing Treatment vs Did Not Die

Variable	Univariate Analysis		Multivariate Analysis	
	p-value	OR (95% CI)	p-value	OR (95% CI)
Gender	0.026	4.216 (1.188, 14.956)	0.021	4.781 (1.262, 18.104)
Relationship to TB Patient	1.000	1.307 (0.362, 4.721)	0.847	1.146 (0.288, 4.554)
Age	0.214	1.961 (0.760, 5.062)	0.128	2.215 (0.794, 6.179)
Level of Education	0593	1.309 (0.472, 3.633)	0.543	0.698 (0.219, 2.222)
Children under 5 years	0.811	1.210 (0.470, 3.113)	0.977	0.984 (0.327, 2.958)
Radio	0.497	1.590 (0.491, 5.153)	0.630	1.372 (0.379, 4.966)
Roof	1.000	1.929 (0.243, 15.307)	0.571	1.725 (0.262 11.342)
Floor	0.486	0.312 (0.004, 2.425)	0.295	0.312 (0.035, 2.763)
Source of Income	0.629	1.406 (0.546, 3.618)	0.637	1.291 (0.447, 3.724)

5.2.3 Characteristics of Tuberculosis Patients Included in the Study

Characteristics of the TB patients identified from the District Register and included in this study are summarized in Table 5.6; 107 (51.7%) of patients were male. TB patients ranged in age from 19 to 77 years, with an average age of 34.8 years (SD ± 12.67). The majority of patients had either sputum-smear positive or sputum-smear negative pulmonary tuberculosis (59.4% and 28.0%, respectively). Patients were primarily newly diagnosed cases of tuberculosis (71.5%), although 2 (1.0%) patients sought re-treatment due to previous treatment failure, 12 (5.8%) required re-treatment due to relapse, and 15 (7.2%) required re-treatment because they defaulted during their previous course of treatment. Of these fifteen patients, eleven defaulted again (and where therefore considered "non-adherent" in this study), one completed treatment, two died before completing treatment, and the status of the final patient was unknown.

Table 5.6 Characteristics of TB patients included in the study

Characteristic	N (%)
Gender	
Male	107 (51.7%)
Female	100 (48.3%)
Class	
Pulmonary, sputum-smear positive	123 (59.4%)
Pulmonary, sputum-smear negative	58 (28.0%)
Extra-pulmonary	2 (1.0%)
Unknown	24 (11.6%)
Category	
Defaulter	15 (7.2%)
Failure	2 (1.0%)
Relapse	12 (5.8%)
New	148 (71.5%)
Unknown	30 (14.5%)

Of the sputum-smear positive pulmonary cases, 52.8% were male, and 88.6% were between the ages of 15 and 54 years. The age and sex distributions of these cases are found in Table 5.7.

Table 5.7 Age and sex distribution of new smear-positive pulmonary cases in study

Age Group	15-24	25-34	35-44	45-54	55-64	65+	TOTAL
Male	9	22	16	9	3	2	65 (52.8)
Female	16	18	14	5	2	1	58 (47.2)
TOTAL (%)	25 (20.3)	40 (32.5)	30 (24.4)	14 (11.4)	5 (4.1)	3 (2.4)	123 (100)

There were no significant differences in class or gender of patients who were non-adherent, adherent, or died before completion of treatment. However, re-treatment cases (including those who had previously defaulted, relapsed, or failed treatment) were more likely to be non-adherent than newly diagnosed cases ($p = 0.021$, OR = 2.252 (1.129, 4.492)). Summaries of univariate and multivariate analyses can be found in Table 5.8 (Adherent versus Non-Adherent groups) and Table 5.9 (Died versus Did Not Die groups).

Table 5.8 TB Patient Characteristics – Adherent vs Non-Adherent Groups

Variable	Univariate Analysis		Multivariate Analysis	
	p-value	OR (95% CI)	p-value	OR (95% CI)
Gender	0.459	1.258 (0.700, 2.261)	0.879	0.951 (0.497, 1.820)
Age	0.543	0.824 (0.450, 1.510)	0.281	0.689 (0.350, 1.355)
Class	0.227	1.478 (0.811, 2.693)	0.312	1.431 (0.709, 2.890)
Category	0.021	2.252 (1.129, 4.492)	0.026	2.451 (1.110, 5.409)

Table 5.9 TB Patient Characteristics – Patients Who Died Before Completing Treatment vs Did Not Die

Variable	Univariate Analysis		Multivariate Analysis	
	p-value	OR (95% CI)	p-value	OR (95% CI)
Gender	0.342	0.596 (0.225, 1.580)	0.382	0.624 (0.217, 1.798)
Age	0.810	1.126 (0.432, 2.932)	0.721	0.823 (2.83, 2.393)
Class	0.225	2.029 (0.702, 5.866)	0.211	2.096 (0.658, 6673)
Category	0.597	1.551 (0.493, 4.882)	0.484	1.577 (0.441, 5.641)

A comparison of TB patients identified by this study and TB patients reported to the NTLP in Kabarole District, 2001, can be found in Table 5.10. The district TB registry classified each patient according to their Class and Category, however, this information was not available in the Kabarole report. Therefore, a meaningful comparison between study patients and all TB patients in Kabarole District cannot be made.

Table 5.10 Comparison of TB Patients Identified for Study and Kabarole District NTLP Report

Characteristic	Study Patients (%)	Kabarole District (%)
Male	52.8	60.7
Female	47.2	39.3
15 – 44 years	77.2	78.9
45+ years	22.8	21.1

5.2.4 Knowledge of TB among Study Participants

Several questions in the questionnaire focused on determining the extent to which family members of TB patients know and understand the disease process of tuberculosis. Study participants were asked general questions regarding causation, transmission, symptoms, diagnosis, and treatment of the disease, as well as its association with HIV/AIDS.

Causation

Participants were asked a single open-ended question to determine their knowledge of the cause of TB. Answers were variable and are outlined in Table 5.11.

Table 5.11 Responses to the open-ended question "What causes TB?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
I don't know	37 (46.8)	33 (31.1)	7 (36.8)	77 (3.7)
Smoking and/or drinking	20 (25.3)	31 (29.2)	4 (21.1)	55 (27.0)
Virus	5 (6.3)	11 (10.4)	3 (15.8)	19 (9.3)
Air	6 (7.6)	9 (8.5)	3 (15.8)	18 (8.8)
Other	4 (5.1)	8 (7.5)	0 (0.0)	12 (5.9)
Body weakness	3 (3.8)	4 (3.8)	1 (5.3)	8 (3.9)
Environmental	1 (1.3)	6 (5.7)	0 (0.0)	7 (3.4)
Genetics	2 (2.5)	2 (1.9)	0 (0.0)	4 (2.0)
AIDS	1 (1.3)	2 (1.9)	1 (5.3)	4 (2.0)

Respondents most commonly stated that they did not know the cause of TB (37.7%), and only 19 (9.3%) correctly identified a biological agent as the cause; 12.2% of participants suggested a route of transmission (either an environmental route, such as houseflies, unclean water or dust, or via the air) as the cause of infection. Most other responses reflected conditions that would

make a person more susceptible to infection, including smoking, drinking, general body weakness, genetic factors, and AIDS. "Other" responses included coughing (4), carelessness (1), using a victim's cup (1), close contact with people with TB (3), sharing food with the TB patient (1), poverty (1), and being imprisoned with a patient (1). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Transmission

Participants were asked an open-ended question to determine their knowledge of the transmission of TB. When participants were asked how TB is spread, the majority (67.0%) stated that transmission occurred by sharing cups, plates, utensils, and food with an infected person; 10.2% of respondents stated that TB was spread through the air. Coughing (3.6%) and smoking (2.5%) were also reported answers; 14.2% of respondents stated that they did not know how TB was spread. These results are summarized in Table 12.

Table 5.12 Responses to the Open-ended Question "How is TB transmitted?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
Airborne	3 (4.0)	15 (14.6)	2 (10.5)	20 (10.2)
Smoking	0 (0.0)	5 (4.9)	0 (0.0)	5 (2.5)
Sharing	52 (69.3)	68 (66.0)	12 (63.2)	132 (67.0)
Coughing	5 (6.7)	0 (0.0)	2 (10.5)	7 (3.6)
Genetics	0 (0.0)	1 (1.0)	0 (0.0)	1 (0.5)
Unsure	13 (17.3)	12 (11.7)	3 (15.8)	28 (14.2)
Other	2 (2.7)	2 (1.9)	0 (0.0)	4 (2.0)

When asked who can get TB, the responses were variable. Participants either identified specific groups of people, including women (1.0%), the elderly (1.4%), caretakers (1.4%), and people with AIDS (1.4%), or more general groups of people, such as those with unhealthy habits or lifestyles (21.7%) or those who are in close contact with TB patients (6.8%); 48.3% of respondents believed anybody could get TB, and 12.6% were unsure. Making this question more personal, participants were asked if they were more likely to get TB than others. The majority (50.2%) of participants responded that they were unsure. 21.2% felt they were more likely to get TB, and 28.6% felt that they were not. These results are summarized in Table 5.13.

Table 5.13 Responses to the Closed Question "Are you more likely to get TB than others?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
Yes	17 (21.8)	21 (19.8)	5 (26.3)	43 (21.2)
No	21 (26.9)	34 (32.1)	3 (15.8)	58 (28.6)
I don't know	40 (51.3)	51 (48.1)	11 (57.9)	102 (50.2)

In addition, 74.4% of respondents feared that other members of their family could become infected with TB. Those who felt they were more likely to get TB most commonly stated they felt this way because of their closeness to the patient (81.8%). Other notable responses included having self-identified risk factors (9.1%) or already exhibiting symptoms (2.3%). Of those who felt they were not more likely to get TB, most felt that this was because they either had no self-identified risk factors (48.2%) or they had taken precautions to protect themselves (19.6%). Such precautions included not sharing beds, utensils or drinking cups with an infected person, not coming into close contact with the infected person, not smoking, or simply "being careful".

Participants were also asked if they could prevent the spread of TB if they were infected; 87.9% stated that they could prevent transmission. They stated that transmission could be stopped primarily by not sharing cups and utensils with others (77.0%). Other methods of prevention suggested included getting treatment or following doctors' orders (12%), isolating one's self (4.5%), and not coughing or spitting around others (3.8%). Only 2.9% felt that there was nothing they could do to prevent the spread of TB.

There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died for all questions ($p > 0.05$).

Symptoms

Two questions were asked regarding the symptoms of TB. Nearly all respondents (98.6%) stated that TB could cause severe damage to the lungs. The remaining 1.4% of respondents were unsure if this was a possible consequence of TB infection. In addition, 96.1% of participants believe that TB can result in death; 2.4% stated that people cannot die from TB infection, and the remainder were unsure. There were no significant differences in the responses

between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Diagnosis

Two questions were asked regarding the importance of being tested for TB. In the first open-ended question participants were asked to identify who should have the TB test. The responses were variable and included those that already have the disease, those at risk for becoming infected, and those exhibiting symptoms of TB. Responses to this question are summarized in Table 5.14

Table 5.14 Responses to the open-ended question "Who should have the TB test?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
Those coughing	27 (34.6)	52 (49.1)	6 (31.6)	85 (41.9)
Everyone	15 (19.2)	15 (14.2)	4 (21.1)	34 (16.7)
Those who have TB	14 (17.9)	14 (13.2)	2 (10.5)	30 (14.8)
The sick or week	9 (11.5)	5 (4.7)	2 (10.5)	16 (11.5)
Those close to the patient	4 (5.1)	6 (5.7)	0 (0.0)	10 (4.7)
I don't know	2 (2.6)	4 (3.8)	2 (10.5)	8 (3.9)
Other	6 (7.7)	5 (4.7)	3 (15.8)	14 (6.9)
Smokers	1 (1.3)	5 (4.7)	0 (0.0)	6 (3.0)

"Other" responses included people who voluntarily request it, people with AIDS, married people, patients vomiting blood, people without TB, and children. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

When asked if getting the TB test would help protect the family from becoming infected, 80.2% of participants responded positively; 8.7% did not feel that having the TB test would be beneficial to their family, and the remaining 11.1% were unsure. Of those stating that having the TB test would be beneficial, the reasons given were: precautions could be taken to protect the rest of the family from becoming infected (48.5%); patients can receive treatment if they know they are infected (30.5%); and having the test puts people in contact with a health care worker, allowing them to ask questions about the disease (20.4%). Of those who do not believe having a TB test will help protect the family, the primary reasons stated were: others can still become infected regardless of whether or not they are tested (44.4%); people can only be helped if they

receive treatment (38.9%); and people can still be a carrier (11.1%). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Treatment

Several questions were asked regarding the treatment of TB; 90.3% of respondents believe that TB can be cured, while 6.3% stated that TB could not be cured. The remaining participants were unsure. When asked how TB is treated (open-ended question), the majority of participants stated that it could be cured by drugs, tablets and/or injections (80.9%). A summary of these responses appears in Table 5.15.

Table 5.15 Responses to the open-ended question "How is TB treated?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
Tablets	24 (30.8)	42 (39.6)	8 (42.1)	74 (36.4)
"You take drugs"	23 (29.5)	18 (17.0)	5 (26.3)	46 (22.7)
Tablets and injections	12 (15.3)	22 (20.8)	4 (21.1)	38 (18.8)
Going to the hospital	10 (12.8)	9 (8.5)	1 (5.3)	20 (9.8)
Unsure	6 (7.7)	8 (17.5)	1 (5.3)	15 (7.4)
Injections	2 (2.6)	4 (3.8)	0 (0.0)	6 (3.0)
Other	1 (1.3)	3 (2.8)	0 (0.0)	4 (2.0)

There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Participants were also asked if it is important to finish the TB treatment, even if they felt well. 86.1% responded "yes", 7.4% responded "no", and the remainder (6.4%) were unsure. These results are summarized in Table 5.16. Of those stating that it is important to complete treatment, the most common reasons given were: to ensure that patients are completely cured (59.3%), and that it is important to follow doctors' orders (38.4%). Participants who felt that it was not necessary to complete the full course of treatment primarily stated that if you feel well, then you are cured, and there is no need to continue treatment (80.0%). The remaining 20% stated that the medication makes patients feel weaker and should therefore not continue taking them. There

were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Table 5.16 Responses to the Closed Question "Is it important to finish TB treatment, even if you feel well?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
Yes	63 (80.8)	94 (88.7)	17 (94.4)	174 (86.1)
No	7 (9.0)	7 (6.6)	1 (5.6)	15 (7.4)
I don't know	8 (10.3)	5 (4.7)	0 (0.0)	13 (6.4)

When asked how long the TB treatment is, the responses were variable, and ranged from less than one month to greater than eight months; 22.7% correctly stated a treatment course of 8 months, and 28.6% stated that they did not know the length of the treatment. These responses are summarized in Table 5.17. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Table 5.17 Responses to the open-ended question "How long is the TB treatment?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
1-8 months	30 (38.5)	28 (26.4)	8 (42.1)	66 (32.5)
Unsure	19 (24.4)	33 (31.1)	6 (31.6)	58 (28.6)
8 months	16 (20.5)	25 (23.6)	5 (26.3)	46 (22.7)
> 8 months	10 (12.8)	17 (16.0)	0 (0.0)	27 (13.3)
"Until they are cured"	3 (3.8)	2 (1.9)	0 (0.0)	5 (2.5)
< 1 month	0 (0.0)	1 (0.9)	0 (0.0)	1 (0.5)

Participants were also asked if they thought traditional healers could help cure TB. The majority (71.5%) felt that traditional healers were not helpful; 25.6% of the respondents stated that they were unsure, while only 2.9% felt that traditional healers could help TB patients. All six participants that believed traditional healers could help stated that they could provide TB patients with local herbs to treat their infection. Of those that felt traditional healers were not helpful, the primary reason given was that traditional healers do not have the proper medications required to treat TB (54.4%). Several participants expressed a distrust of traditional

healers (4.8%), and others stated that they either enlisted the help of a traditional healer and did not get better (2.0%), or had heard similar stories from other people (16.3%). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

TB and HIV/AIDS

Participants were asked two questions to determine their understanding of the relationship between HIV and AIDS. The majority of participants (63.3%) understood that it is easy to get TB if one has HIV; 34.8% were unsure; 56% of participants felt that people with HIV should be treated for TB, 18.8% felt that treating HIV patients was not appropriate, and the remaining 25.1% were unsure. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died.

Participants were also asked how they felt about patients having both TB and HIV/AIDS. Participants expressed much fear surrounding HIV and only rarely mentioned TB. Several respondents commented on all of the loved ones they have lost to AIDS and their fear that they will experience the same fate. Some also stated that TB is not something to worry about because "TB can be treated but AIDS cannot be". Others stated that "it is God's plan that some must suffer". Many respondents also expressed concern and sympathy for those affected by these diseases.

When asked what advice to give to patients with both TB and HIV/AIDS, the majority of participants stated that these patients need to seek immediate medical care. They also said it was important to eat well and "rest much". Many said that is important to avoid "sharing", sex, "boozing" and "working hard". Two respondents said "treat TB but don't treat AIDS". Many participants also responded that these patients need to pray or seek forgiveness.

Nutrition

At the request of Ugandan research team members, participants were asked what foods a TB patient should eat. Responses were variable and are summarized in Table 5.18

Table 5.18 Nutritional Advice for TB Patients

Common Participant Responses
• Foods that "build the body" including cabbages, avocado, milk, meat, fish, and eggs;
• "Soft foods" such as fish and matooke, because this is all a weak person can eat and it helps with pain;
• "Milk and meat will help the pain in the chest";
• Foods that "give energy" such as milk, eggs, greens, and beans;
• "Everything except potatoes and yams because these foods cause coughing";
• Foods that "give more blood" such as ground nuts, peas and beans;
• Any foods that are affordable;
• Whatever the patient prefers;
• "Many drinks and soft foods to not be weakened by the drugs";
• "Foods that have starches and carbohydrates because that's what the radio says";
• "Sticky food to fill the holes in the chest"; and
• "Good feeding because the tablets weaken the body".

5.2.5 Attitude of Families Towards TB

Several questions were asked to determine the extent of stigmatization by examining the attitude of families towards people with TB; 73.2% of participants said that they knew other people in the community with TB; 24.6% of participants stated that they knew someone with both HIV and TB.

More than half (58%) of the respondents stated that they were worried about acquiring TB. When asked why, participants most commonly stated (44.5%) that their association with a TB patient puts them at a higher risk for acquiring the disease. 20.2% also stated that they worried because TB is a fatal disease, or is very difficult to cure. Other common reasons included: a general concern about all diseases (11.8%); they were already exhibiting symptoms (4.2%); or they participate in activities that put them at a higher risk of contracting the illness (4.2%); 42% of participants that suggested they were not worried about getting TB most commonly stated that their lack of worry stemmed from a belief that they have no control over their health, or that if they become infected, it is "God's will" (31.8%). Other common reasons included: no identifiable risk factors (25.9%); precautions were taken to protect themselves (21.2%); or a lack of presentation of symptoms (4.7%). There was a trend towards a significant difference

between families of patients who completed their treatment, died before completion, and those who were non-adherent ($p = 0.051$). When patients who died were considered adherent, there was a significant difference between families of patients who were adherent and those who were non-adherent ($p = 0.021$). Participants who expressed worry had 1.94 the odds of having a non-adherent TB patient in the family (95% CI: 1.10 – 3.43).

Participants were also asked if they feared TB. 62.3% of respondents said that they were afraid of acquiring TB. When asked to explain their fear, the majority (55%) stated that feared the symptoms or the potential fatality of the disease. 30.5% also perceived an increased risk of getting TB. They also expressed a fear of the cost associated with treating TB (3.1%) and of the difficulty in nursing TB patients (3.1%). The participants who were not afraid of becoming infected most commonly stated that either a lack of risk factors (25%) or taking precautions (21.7%) were reasons for their lack of fear. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Despite fear and worry surrounding TB infection, only 14% of respondents stated that they have had the TB sputum smear test. Only one participant said they were unsure if they had ever been tested for TB; 76.2% of participants stated that they did not have TB, 1.9% stated that they did have TB, and the remaining 21.8% were unsure. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

To elucidate the stigma attached to TB, participants were asked if they would want their neighbors to know if they had TB. The vast majority (78.2%) stated that they would want their neighbors to know of their TB status. When asked for reasons, most felt that telling their neighbors would help them from becoming infected (48.4%). They also felt that their neighbors would be able to provide assistance if they were aware (18%); 24.2% stated that it was not possible to hide any disease, so there is no advantage to not telling neighbors. The 21.8% who felt it was best to not tell their neighbours about their infections stated the following reasons why they felt this way: 48.9% wanted to avoid rumours; 31.1% were afraid of being isolated from their neighbours; 4.4% stated that it was a private matter that shouldn't be shared. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Participants were also asked if they felt TB patients should be isolated from other people. More than half (52.9%) felt that patients should be isolated, 36.9% felt isolation was not necessary, and the remaining 10.2% were unsure. People who favored isolation most commonly stated that isolating patients would help prevent the spread of infection to others (88.9%); 6.5% stated that since patients are isolated when they are in the hospital, they should be isolated at home as well. Those who felt that isolation was not necessary, largely believed that TB patients need the comfort and care of friends and family and should therefore not be isolated from them (76%). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

When asked if having TB would affect their relationship with others, 62.1% thought that it would. 33.5% stated that their relationships would not be affected, and the remaining 4.4% were unsure. Those who felt their relationships would be affected most commonly stated that this would be due to either a lack of energy to devote to the relationship (43.8%) or isolation (43.8%). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Participants were asked to describe how their family would feel if they had TB. The majority (58.9%) stated that their family would express strong negative emotions, such as fear or hatred. 16.8% did not know how their family would feel; 13.9% stated that their family would "feel bad" for them or express sympathy; 3.5% stated that their family would care for them. There was a significant difference between families of adherent patients and non-adherent patients ($0.01 < p < 0.025$). When patients who died were considered to be non-adherent, there was also a significant difference ($0.005 < p < 0.01$). Results are summarized in Table 5.19. It is important to note that feelings of fear or hatred, most relevant to stigma, did not differ between groups.

Table 5.19 Answers to the Open-ended Question "How would your family members feel if you had TB?"

Response	Adherent N (%)	Non-Adherent N (%)	Died N (%)	Total N (%)
"They would care for me"	0 (0.0)	6 (5.7)	1 (5.3)	7 (3.5)
Fear/hatred	48 (61.5)	61 (58.1)	10 (52.6)	119 (58.9)
Sympathy	7 (9.0)	15 (14.3)	6 (31.6)	28 (13.9)
Other	12 (15.4)	2 (1.9)	0 (0.0)	14 (6.9)
Unsure	11 (14.1)	21 (20.0)	2 (10.5)	34 (16.8)

5.2.6 Family Support for TB Patients

Several questions were asked to determine how well family members support their TB patient during treatment. When asked what should be done to address concerns about family members having TB, the most common answer was to encourage the patient to seek treatment for the disease (38.6%). Another 23.2% stated that they would do nothing to address concern; 14% stated that they would be cautious around them to protect themselves and 6.8% stated that they would seek medical advice for them. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Almost all (99%) of the participants stated that the TB patient in their family took tablets for treatment, and the vast majority knew that the patient received their tablets from either a hospital (53.6%), a health unit (35.7%), or both (7.2%). Other responses included from the pharmacy (1.4%), or from a community health worker (1%). The remaining 1% were unsure. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

Participants were also asked if they could identify when the patients took their tablets. Responses were variable and included: in the morning (32.4%), in the evening (30.9%), anytime (2.4%) or in both the morning and evening (19.3%); 10.6% stated that they did not know when the patient took his tablets. There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$); 73.2% of participants stated that they reminded the patient in their family to take their tablets.

Only 16.7% of the participants stated that they asked for information about TB from a community health worker. Respondents generally sought advice regarding self-protection against TB and how to care for the TB patient in their family (including nutritional advice).

Less than half (41.7%) of the TB patients were hospitalized for TB according to their family members; 86.7% of these respondents stated that they visited the patient while he/she was in the hospital.

5.3 Witnessed Directly Observed Treatment

Participants were asked if anyone assisted their TB patient in swallowing his tablets; 87% responded "yes", 12.6% responded "no", and one participant was unsure. Family members were most commonly cited as the supervisor (90.4%). Another member of the community or the local chairman were also identified (6.7%) as were community health workers (1.7%). There were no significant differences in the responses between family members of non-adherent patients, adherent patients, and patients who died ($p > 0.05$).

5.4 Witnessed Adherence

When asked if the TB patient ever interrupted his treatment, only 11.3% said yes, despite the fact that 52.1% were identified as being non-adherent in the TB register; 79.4% stated that their TB patient never interrupted his/her treatment, and the remaining 9.3% were unsure. When respondents identified their TB patient as non-adherent, the majority stated that they stopped their treatment because they felt better (29.2%). Other common responses included: financial reasons (12.5%); no access to the drugs, or the drugs were not delivered (12.5%); the patient moved (8.3%); or side effects (8.3%). If the patient was convinced to return to his treatment schedule, it was a family member who convinced him 72.2% of the time. It was a health care worker who convinced him to return to treatment in all other cases. TB patients whose family member stated that they were non-adherent were significantly more likely to be registered as a "defaulter" in the district TB registry ($p = 0.02$, OR = 3.63 (1.16 – 11.39)). The same is true when TB patients who died were considered to be non-adherent ($p = 0.016$ OR = 3.68 (1.20 – 11.32)).

5.5 Scores Derived from Questionnaire Responses

5.5.1 Knowledge

Fourteen questions were combined to calculate a summary score to measure the TB knowledge of each participant. A high score indicates a higher level of knowledge. The maximum score attainable was 16. Participant scores ranged from 3 to 13, with a mean of 8.5 ± 1.9. There was no significant difference in the means of participants with an adherent TB patient in their family and participants with a non-adherent TB patient ($p > 0.05$). There was also no significant difference in the means of participants whose TB patient died and of participants whose TB patients were alive at the end of treatment. Means are summarized in Table 5.20.

Knowledge scores were negatively and significantly correlated with age, indicating that younger participants had higher knowledge scores ($r = -0.238$, $p < 0.001$).

5.5.2 Attitude

Seven questions were combined to calculate a summary score to measure the attitudes of families towards TB. The maximum score attainable was 7, with a higher score indicating a more positive attitude, or reflecting a less damaging stigma. Participant scores ranged from zero to 7, with a mean of 3.1 ± 1.2. Differences in attitude scores between adherent and non-adherent groups were approaching significance ($p = 0.067$), while the difference between patients who died before completing treatment and those that did not was significant ($p > 0.05$). Means are summarized in Table 5.20.

5.5.3 Support

Seven questions were combined to calculate a summary score to measure the level up support participants gave to the TB patient in their family. The maximum score attainable was 8, with a higher score indicating supportive behaviour. Participant scores ranged from 3 to 8, with a mean of 5.4 ± 1.1. There was no significant difference in the means of participants with an adherent TB patient in their family and participants with a non-adherent TB patient ($p > 0.05$). There was also no significant difference in the means of participants whose TB patient died and of participants whose TB patients were alive at the end of treatment ($p > 0.05$). Means are summarized in Table 5.20.

5.5.4 Total Scores

Knowledge, Attitude and Support scores were combined to create a Total TB score. The maximum total score attainable was 31. Participant's total scores ranged from 9 to 25, with a mean of 17.1 ± 2.80. There was no significant difference in the means of participants with an adherent TB patient in their family and participants with a non-adherent TB patient ($p > 0.05$). There was also no significant difference in the means of participants whose TB patient died and of participants whose TB patients were alive at the end of treatment ($p > 0.05$). Means are summarized in Table 5.20.

Total scores were negatively and significantly correlated with age, indicating that younger participants had higher total scores ($r = -0.275$, $p < 0.001$).

Table 5.20 Summary of Knowledge, Attitude, Support, and Total Scores

Comparison	N	Mean ± SD
Knowledge scores		
Adherent	78	8.2 ±1.95
Non-adherent	10	8.7 ± 1.78
	6	
Died before completing treatment	19	8.6 + 2.24
Alive at treatment completion	18	8.5 ± 1.86
	8	
Attitude scores		
Adherent	78	3.0 ± 0.99
Non-adherent	10	3.2 ± 1.27
	6	
Died before completing treatment	19	3.0 + 1.51 *
Alive at treatment completion	18	3.1 ± 1.15
	8	
Support scores		
Adherent	78	5.5 ± 0.98
Non-adherent	10	5.4 ± 1.10
	6	
Died before completing treatment	19	5.1 + 1.15
Alive at treatment completion	18	5.4 ± 1.04
	8	
Total scores		
Adherent	78	16.7 ± 2.85
Non-adherent	10	17.7 + 2.69
	6	
Died before completing treatment	19	17.6 ± 3.15
Alive at treatment completion	18	17.0 + 2.77
	8	

** $p < 0.05$ (died vs alive)*

5.5.5 Relationship Between Other Important Variables and Scores

Differences in mean scores were compared for several socio-demographic factors, including respondents' relationship to the TB patient, the gender of the respondent, highest level of education attained by the respondent, whether or not the household had a radio, and type of floor and roof in the family home. There were significant differences in Knowledge Scores for participants with different levels of education and radio ownership. Both Support Scores and

Attitude Scores differed between male and female respondents ($p < 0.05$). Mean scores for these variables can be found in Table 5.21

Table 5.21 Comparison of Scores for Socio-demographic variables

Comparison	Mean ± SD	Mean ± SD
Relationship to TB patient	**Immediate Family (N = 167)**	**Not immediate family (N = 40)**
Knowledge Score	8.5 ± 1.85	8.7 ± 2.09
Attitude Score	3.1 ± 1.22	3.4 ± 1.15
Support Score	5.4 ± 0.96	5.4 ± 1.38
Total Score	17.0 + 2.79	17.5 ± 2.86
Gender of Participant	**Male (N = 86)**	**Female (N = 121)**
Knowledge Score	8.7 ± 1.80	8.4 ± 1.95
Attitude Score	2.9 + 1.14	3.3 ± 1.24 *
Support Score	5.6 ± 1.14	5.3 ± 0.97 *
Total Score	17.2 ± 2.82	17.0 ± 2.80
Highest Level of Education	**Primary School (N = 120)**	**Secondary or Higher (N = 27)**
Knowledge Score	8.5 ± 1.86	9.4 ± 1.69 *
Attitude Score	3.1 ± 1.18	3.0 ± 1.16
Support Score	5.4 ± 0.91	5.8 ± 1.31
Total Score	17.1 ± 2.59	18.2 ± 2.97
Radio	**Yes (N = 176)**	**No (N = 31)**
Knowledge Score	8.7 ± 1.92	7.6 ± 1.41 *
Attitude Score	3.1 ± 1.19	3.2 ± 1.34
Support Score	5.4 ± 1.04	5.4 ± 1.11
Total Score	17.2 ± 2.91	16.1 ± 1.85 *
Roof	**Thatched (N = 19)**	**Metal (N = 186)**
Knowledge Score	8.5 + 2.41	8.5 ± 1.85
Attitude Score	2.7 ± 1.15	3.2 + 1.22
Support Score	5.5 ± 0.97	5.4 ± 1.05
Total Score	16.7 ± 3.28	17.1 + 2.76
Floor	**Earthen (N = 175)**	**Cement (N = 29)**
Knowledge Score	8.5 ± 1.89	8.6 ± 1.98
Attitude Score	3.2 ± 1.22	2.8 ± 1.15
Support Score	5.4 ± 1.06	5.5 ± 0.91
Total Score	17.1 ± 2.78	16.8 ± 3.01

* $p < 0.05$

5.6 Multivariate Analysis

After controlling for all other variables, the class of the TB patient, the level of education of the study participant, and presence or absence of a radio were significant predictors of Total Score. The F statistic and p-value of each variable from the logistic regression can be found in Table 5.22.

Table 5.22 Multivariate Analysis

Variable	F statistic (df 1, 190)	p-value
Gender of TB Patient	F = 0.001	> 0.05
Age of TB Patient	F = 1.611	> 0.05
Class of TB Patient	F = 5.708	0.01 < p < 0.05
Category of TB Patient	F = 0.002	> 0.05
Gender of Respondent	F = 0.029	> 0.05
Age of Respondent	F = 3.530	> 0.05
Relation to TB Patient	F = 1.424	> 0.05
Level of Education	F = 6.417	0.01 < p < 0.05
Children Under 5	F = 3.152	> 0.05
Radio	F = 3.952	0.01 < p < 0.05
Floor	F = 0.728	> 0.05
Roof	F = 0.199	> 0.05
Source of Income	F = 0.700	> 0.05

CHAPTER 6 – QUALITATIVE RESULTS

The quantitative findings provided valuable information regarding the knowledge, attitudes, and supportive behaviour within the families of TB patients. However, other potentially important factors were discovered during the administration of these surveys. It became clear that study participants experienced real barriers in both initiating and receiving treatment. Although the focus of this study was to determine the role of family support in promoting adherence to TB treatment, the researcher felt it was important to give TB patients, their families, DOTS volunteers and community health workers the opportunity to talk about the concerns they had with TB control. These discussions not only identified barriers to treatment, they also helped put the results of the quantitative study into a more culturally appropriate context.

6.1 Perspectives of District Health Care Staff on Community TB Services

The content analysis of in-depth interviews with community health workers and district TB staff focused on three major barriers within the local health care system: perceived barriers in the process of TB control and DOTS; perceived reasons for non-adherence; and perceived lack of knowledge in community members. Themes emerging from discussions surrounding these barriers are summarized in Table 6.1.

Table 6.1 Major Themes Relating to the Perspectives of District Health Care Staff on Community TB Services

Perceived Barriers in the Process of TB Treatment and DOTS
• *Patients are not hospitalized when they need to be*
• *Community health staff are overworked*
• *Many TB patients in the district do not have access to DOTS*
• *Educational strategies are not followed through*
• *Community leaders do not share health information*
• *Lab services are unequally distributed*
Perceived Reasons for Non-adherence
• *Patients feel better*
• *Sputum smears are negative during monitoring check-ups*
• *Eight months is a long time to take treatment*
• *Transportation*
• *Poverty*
Perceived Lack of Knowledge in Community Members
• *Relationship between TB and HIV/AIDS*
• *Causation*
• *Free access to drugs at all health centers*

6.1.1 Barriers in the Process of TB Treatment and DOTS

Participants were very keen to describe what is "supposed" to happen once a patient is diagnosed with TB. They often made reference to the education they received and they seemed to want interviewers to know how clearly they understand their role in TB control. They often expressed frustration with their perceived inability to fulfill this role.

Heath care staff clearly described how a patient should be kept in a hospital or on a health unit for at least two weeks after being diagnosed with TB. During this time the patient receives health education and is prepared for directly observed treatment at home. There was agreement among staff that this process was not happening.

> *"Unfortunately, that process of first admitting a patient for two weeks is not being followed because not all the health units are admitting, or they don't have the facilities to admit a patient. Where it's possible they can admit, they do, but all the same the condition becomes too much. The drugs that we give are all oral, we don't give injections unless the patient is being retreated, so it is still easy for a patient to take his drugs immediately after being diagnosed without being kept in the hospital first."*

Health care staff also discussed how DOTS volunteers are recruited and trained.

> *"[The patient] will find another volunteer, who's going to be selected by the community, and from there again he will continue the process of being observed, given his treatment, until he completes the eight months. When the patient is in the hospital, a health worker, who is normally a health assistant, is given information about this*

patient, his home address, and everything about his contacts. He goes to the village with the LC1 chairman, that's the leader of the community, and then that person organizes a meeting for him with the community members and he gives a health education talk and explains all about TB and he introduces the directly observed treatment, that's DOTS, for this patient. Then the community selects a volunteer in preparation to receive this patient when he leaves the hospital. Then the patient goes home with enough drugs to keep him up to the time he meets his volunteer and the process continues from there."

When asked what barriers exist in making the transition from treatment in the hospital to treatment under DOTS in the community, respondents commonly noted the tremendous workload of health care workers. Often, health care staff do not have the time to recruit treatment supervisors, resulting in DOTS either being delayed, or not happening at all, for many TB patients.

"The process of DOTS is delayed because a patient is given drugs, then contacts are given to the health assistants who many times will tell you they are also busy, they have other activities. In fact it's true. They have very many other activities they do. So, by the time he actually has the time to go and visit the patient's home, they find the patient has actually taken his drugs by himself, for even two months. So, DOTS is not started immediately to many of our patients. And even sometimes some of the patients, in fact we have almost half the patients in the areas where DOTS has started doing without DOTS."

Participants described other barriers that prevent successful DOTS programmes in the community, particularly in terms of providing patients with an adequate drug supply. Although patients and their supervisors are told that drugs will be delivered to them every two weeks, this does not always happen.

"It's another unfortunate thing. The drugs are not taken every two weeks. Many of them are taking drugs on a monthly basis. And sometimes they may not even go there, they may not ever take the drugs. You find patients or their volunteers coming for their drugs and that one now leaves two options: if they are collected by the volunteer, then the DOTS observation will continue. But if they are collected by the patient, the patient will keep his drugs and take them himself. That mean's he's not being observed This one of the things, actually, we keep meeting in the community, in the field."

Participants also expressed frustration with the sub-counties selected for DOTS, suggesting that many TB patients live in sub-counties not using the DOTS strategy, and even in those counties using DOTS, many patients are not give supervised treatment.

"Not all the sub-counties are covered with DOTS. The Municipality (Fort Portal and surrounding area) *which has got very many patients is not on DOTS. And we have got six sub-counties which are practicing DOTS* (Rwimi, Kibiito, Buhesi, Ruteete, Busoro, and Kibale). *So the remaining, that's half the district, are not on DOTS. So we have half doing DOTS and within this half about half of their patients are on DOTS."*

This frustration of not being able to implement the TB control strategies in place also extends to the efforts to educate the community about TB.

> *"We have a strategy. Before a patient is put on DOTS, health workers are supposed to give health education talks to the community. They're supposed to educate the community on everything about TB. It's not perfectly done. Because some volunteers are hand picked. So we find even though DOTS is in places, the community has not been educated because that part was skipped, unfortunately. So it was the plan, but it wasn't actually implemented. Another strategy is whenever we move out during the supervisions, we talk to the community members. When we visit a patient we make sure we don't leave that village without giving them a word. And we sensitize the sub-county leaders in a hope that when they are also conducting their meeting, the exercise continues, they also give the message to the people. That one we don't have a measure so we don't know how much it has worked. But whenever we visit leaders they tell us, "oh yes, we sill remember your talk and we're doing it in our community, we're telling our people". But I think these people are ignorant, they don't know."*

Finally, comments were made regarding laboratory services in the district. It was felt that they were not equally distributed throughout the district, and this means that patients have a difficult time accessing them to monitor their treatment success.

> *"Our laboratory services in the district here have not been so good. They are not equally distributed. You find three, the main three ones are within the Municipality, but the Municipality covers a small part of the district. The district towards the west and the north, they have no laboratory services. So monitoring patients after they have been diagnosed at two months, five months, and after they complete is not easy. Many of them we don't actually monitor. And that gives us very low results, cure rates. We are not examining.*

6.1.2 Perceived Reasons for Non-adherence

Participants were asked to describe their observations and thoughts regarding why patients in their community do not complete their treatment. The most common reason stated was that the patient feels better, and therefore believes he/she is cured. Again, participants expressed frustration that such beliefs exist in the community, despite attempts to educate them about the importance of completing treatment.

> *"The treatment of TB takes long. By two months many of the patients are feeling much better. All the symptoms are gone. And yet we still insist please come back and continue and finish up. So to them they have their thermometer. I use this word in the community when I am talking to them. Their thermometer is how they feel bodily. The patient, if he's feeling better, he tends to default."*

Participants also suggested that despite education, patients believe that sputum conversion indicates that they are cured, especially when they are also feeling better.

> *"We have a tendency of putting negatives to results where we have not found a complete bacilli. So we put negative. And that one by every person, he's cured, the*

organisms are not there. So to them that one plus the way they feel, they're cured! But we tell them in reality they are not cured. Because we know the bacilli is in pieces up to almost eight months. So we tell them if you don't remove all the pieces, if you don't take the process up to the point when the pieces are in dust form, then the moment they are off the drugs, those pieces grow again and the disease comes up even worse because it is resistant to the drugs."

Participants also cited the fact that it is simply tiring taking drugs for a long period of time.

"Another reason they default is they get tired of taking the drugs. It's not easy. Some people even fail to finish a course of malaria. They cannot take antimalarials up to the time they are prescribed. Even antibiotics when you have to take them for about five to seven days. They cannot. So how about those who are taking [drugs] for eight months on a daily basis. So they get fed up."

Poverty and problems with transport to the nearest health unit was also identified as a barrier to continuous TB treatment. It was also suggested that patients also have difficulties leaving their homes for a long period of time, particularly when there is no one available to look after their home and protect their livelihood while they are away.

"Some patients come from far. They don't have transport, their income is very low. In fact, TB is considered a disease of the poor. They have no means of going to collect their drugs. Many other things come in. Rain, like now it is the rainy season. That alone can be a problem to many. Some people have no people to leave behind. Although they are patients, they have a way they live. They have something that makes them live, so they may have a few things that they keep at home. There is nobody to look after them the moment they move away. That can be a problem. If he is diagnosed with TB it is like a punishment because he has to leave his home which has nobody to attend."

Finally, one participant felt it was simply a general lack of knowledge:

"Some patients are resistant to get volunteers [DOTS supervisors]. *Some patients are not easy to deal with. Some patients are ignorant, but we try to educate them.*

6.1.3 Perceived Lack of Knowledge in Community Members

When asked to describe what knowledge they felt the community was lacking, or to list some of the questions community members commonly ask about, participants had much to say about TB's relationship to HIV/AIDS.

"[Some people] *associate it with AIDS, with HIV. It is one of the reasons why patients don't come out too readily for diagnosis, for treatment, Many of them don't show up and even when they are put on treatment they don't want to tell others that they have TB because they think they'll be associated with AIDS. Even relatives will even discourage patients, "Don't go for treatment, you're going to die". It's wasting money. He's wasting our time. So there are questions in relation to HIV. There is lots of talk."*

Participants also stated that community members commonly ask about the causes of TB.

"They'll ask about the causes because many of them don't know what causes TB. They think that by sharing cups and plates. They think it is witchcraft. They think some people are born with it. So there are many questions."

Finally, it was also mentioned that people express confusion over where they can obtain drugs for TB, and that these drugs are provided free of charge. This confusion stems from the fact that normally when patients are prescribed medications, they are instructed to purchase them from a pharmacy. In addition, problems with maintaining consistent stocks in the health units have given the impression that patients must look for their medications elsewhere.

"Most of our people think our health units are not stocked with drugs. There was a period, even right now, you go to the government health units, you don't get all the treatments you want. They are prescribed for you and they will show you where you can buy the drugs. Even our regional referral hospital, Fort Portal Hospital, that's how it is. You are admitted there, you will buy the drugs from outside. You'll get very few drugs from the health unit. So they have the belief that health units do not have drugs. So they think that all diseases you have to buy drugs elsewhere. Also, almost all the leaders know that the drugs are there and free. Give the message to the leaders and they will pocket the message. They don't pass it out to their people."

6.2 Perceptions of TB Patients and Their Families

Data acquired from in-depth interviews with TB patients and their families was limited, primarily due to an inability to overcome the language barrier, in such a short period of time. For the most part these interviews were simply reiterations of the questionnaire. However, some interesting points emerged, particularly related to the relationship between TB and AIDS and the effect TB has had on the family.

6.2.1 TB and AIDS

There is clearly confusion surrounding the relationship between TB and AIDS in rural Uganda. Although participants seem to understand that there is a connection, there is very little understanding as to what this connection is. In the questionnaire, several participants stated that AIDS causes TB, and that people with AIDS are more likely to become infected with TB. In the in-depth questionnaire, participants were encouraged to share their ideas as to why they felt this way. It was common for participants to say that there are two types of TB, one that is caused by AIDS, and one that is not. The TB that is caused by AIDS is seen as incurable, and ultimately leading to death. The "other TB" is curable, and not to be worried about.

In some cases, participants were unwilling to discuss TB and AIDS. It is unclear whether this unwillingness is due to a fear of the stigma attached to these diseases, or simply a lack of

knowledge. It was not uncommon to have a participant state "I have nothing to say about AIDS and TB" when asked to share what they know about these diseases.

6.2.2 Perceived Effect of TB on the Family

Many participants felt that TB did not have a major effect on the family:

> *"It has caused no impact on the family and nobody contracted it. The person stayed with us just like any other person but he would sleep in his own room."*

> *"People treated me well."*

> *"I have not had any problems nursing her [the TB patient]."*

> *"I haven't met many problems. It hasn't disturbed me. Life is almost the same".*

> *"The government helps us by giving free drugs."*

Other participants acknowledged only minor negative effects on the family:

> *"He did not do any work at home."*

> *"I send kids away when they come closer to me."*

One participant commented on the financial burden TB has placed on his family:

> *"The major problem I have found is financial, and tiresome movements to the hospitals."*

Some participants commented on feeling isolated:

> *"People tried to isolate me, but I spend a long time in the hospital."*

Some participants felt the effects of TB quite strongly:

> *"The problem I have with TB is the death of my husband."*

CHAPTER 7 – DISCUSSION AND RECOMMENDATIONS

Currently in Kabarole District, more than 1,400 cases of TB are registered annually. Statistics gathered in 2001 demonstrate that 7.2% of all cases treated during that year were identified as "defaulters" and were receiving re-treatment as a result. Examining the District TB register (2002-2003) revealed that nearly 10% of all registered TB patients either did not complete their full course of treatment are missed at least three consecutive months of treatment. Clearly, despite the integration of the DOTS strategy into the TB control programme, non-adherence remains a significant threat to successful management of this disease.

7.1 Comparison of TB Patients Identified in the Study with District Data

An unpublished investigation lead by the National Union Against Tuberculosis and Lung Disease (IUATLD) collected reports of case-finding of TB in Uganda for the first six months of 2002. A comparison of this data with the patients identified in this study can be found in Table 7.1.

Table 7.1 Comparison of Study Patients with IUATLD Findings

Characteristic	Study TB Patients, Kabarole District	IUATLD Data, Kabarole District	IUATLD Data, Total Uganda
Total cases	207	443	17,154
New smear-positive cases	123 (59 %)	180 (41%)	9,554 (56%)
Relapsed cases	12 (6 %)	19 (4%)	868 (5%)
Smear-negative cases	58 (28 %)	240 (54%)	5,191 (30%)
Extra-pulmonary cases	2 (1%)	4 (1 %)	1,541 (9%)

Compared to national data, Kabarole District reports lower proportions of new smear-positive and extra-pulmonary cases, and a higher proportion of smear-negative cases. TB patients in this study more closely resemble national TB data, similarly reporting more smear-positive cases and less smear-negative cases.

7.2 Adherence

Adherence to TB treatment is a complex phenomenon and involves interactions between three important levels within the healthcare system: the TB control program, the health care workers and community workers, and the patient. These levels must all be taken into consideration when interpreting adherence data. The patient may be non-adherent for personal reasons, such as a feeling of obligation to family or work. However, non-adherence can also occur even when the patient is committed to completing treatment. If the health care worker is not adequately trained, or if the patient does not have a good relationship with his/her treatment supervisors, the patient may default from treatment. Likewise, if the program does not make a constant supply of anti-TB drugs available, non-adherence may result. All three levels of adherence must be optimal in order for TB treatment to be successful.

The literature shows that at least one-third of all patients, unpredictable by age, gender, race, ethnic background, income, education, social status, occupation, or symptoms of TB, will fail to adhere to their treatment regimen (Sbarbaro 1998, Liam 1999, Tekle 2002, Chee 2000, Nuwaha 1999, Nuwaha 1996, Peltzer 2002). Similar results were found in this study. With the exception of having an earthen floor ($p = 0.034$), non-adherent families were not significantly different from adherent families in any socio-demographic factors. Families with an earthen floor (as opposed to a cement floor) had 2.6 the odds of being non-adherent. If an earthen floor is indicative of a lower socio-economic status, then this might suggest that poorer families are more likely to have non-adherent TB patients. However, none of the other variables meant to describe socioeconomic status showed any significant difference between adherent and non-adherent groups.

In addition, adherent TB patients identified in the TB registry did not differ from non-adherent patients in class, age or gender. They did, however, differ in TB category. Re-treatment cases, including patients that had previously been identified as defaulters, treatment failures, or relapses, have 2.5 the odds of being non-adherent than do newly diagnosed TB cases.

Despite little difference between these groups, it is important to identify factors that could possibly contribute to, or encourage, non-adherent behaviour. It is the responsibility of TB control programmes to be aware of the obstacles that may stand in the way of patients completing their scheduled doses. Treatment behaviour is a complex phenomenon and

successful strategies to enhance patient adherence need to address these barriers, as well as the unique experience of their patients.

When asked why the TB patient in their family interrupted his or her treatment, many of these commonly identified factors were given as reasons, including improved symptoms and limited access to the drugs. These reasons were also given by the health workers interviewed as primary explanations for non-adherent behaviour. Studies in Ethiopia (Demissie 1994, Tekle 2002) and Singapore (Chee 2000) have found that non-adherent behaviour occurred most frequently in the third or fourth month of treatment, likely corresponding to a time when their symptoms have completely disappeared. Patient education should emphasize the importance of treatment completion. It may also be important to encourage DOTS supervisors and health care workers to pay closer attention to TB patients during their third and fourth months of treatment, and to remind patients that even though they may be starting to feel much better, they need to continue taking their tablets.

In addition, family members also stated that moving to a new home, financial reasons, or side-effects contributed to their non-adherence. A study conducted in Mbarara District, neighbouring Kabarole District in western Uganda, reported a default rate of 42.9%, before the introduction of DOTS (Nuwaha 1997). Factors associated with compliance included being smear positive, previous TB treatment, and use of short course treatment. Patients were more likely to default if they moved to an area where they would need to visit a different health unit to receive treatment (OR = 22.3), or if they moved to another district. Similar results were found in a study in Malawi, in which up to 23% of patients were found to move during the course of their treatment (Meijnen 2002). This is still one of the most common reasons given to explain treatment interruption in Uganda, even after increasing political commitment to the DOTS strategy and the TB control programme in general. This is one very important aspect of the control programme that needs to be addressed. It is well known that there is a trend towards urbanization, especially among economically active members of the community. This age group has the highest prevalence of TB, meaning that there is likely to be high movement of TB patients. Therefore, TB patients, particularly ones of this age group, need to be educated so that they understand the importance of treatment completion, and it should be explicitly explained that if the patient must move, it is imperative that he takes his TB treatment card to the health center nearest his new residence to continue treatment. Similar problems have also been found in Zimbabwe (Armstrong 1984). Movement of patients before treatment completion is not only

an issue of the developing world; this has also been shown to be a primary reason for default in California TB patients (Cummings 1998).

Side effects have also been noted as reasons for non-adherence in other African studies. Nearly 8% of defaulters in an Ethiopian study reported side-effects, and this was explained by high HIV seroprevalence (Tekle 2002).

It has been suggested that hospitalizing patients for the initial intensive treatment (two months) increases adherence for the remaining six months of treatment (Murray 1990). Although hospitalization is the intention of the TB control programme in Kabarole District, this is not often done. Interviews with health care workers revealed that hospitals simply do not have the capacity to admit patients. In addition, less than half of survey participants noted that their patients were hospitalized for TB. However, a study in the Rakai district of western Uganda found that excellent adherence rates (92%) are achieved with ambulatory treatment during the intensive phase (Nuwaha 1999). In this district, only 3% of TB patients were hospitalized. It should be mentioned that other important aspects of the TB control programme in Rakai district may contribute to this high adherence rate, most notably (Nuwaha 1999):

1. Health care centers in Rakai district are more equitably distributed than in other districts of Uganda; 80% of the population lives within a one-hour walk of a health centre. This limits problems with transportation and access to health care centers for treatment;
2. Increased emphasis is placed on training and educating health care staff at the centres; and
3. Every effort is made to allow the patient to receive their intensive treatment, as well as their continuation treatment at the health center nearest to their home. In many other districts, including Kabarole, only certain facilities have diagnostic capabilities, and often the intensive phase will take place at this center, then the patient is referred to a center close to home for the continuation phase.

Another study in South Africa found that decentralizing TB care from hospitals to local health clinics did not affect successful treatment outcomes (Edginton 1999). This was found to be more acceptable to the patients, but also required a high level of organization to provide the necessary laboratory network, adequate drug supplies, and staff training, supervising, and monitoring.

There is also evidence to suggest that hospitalization is not preferred by patients. Interviews with health care workers revealed several negative effects hospitalization can have on the family. There is tremendous strain put on the family when a patient is hospitalized, especially if the patient is the major breadwinner of the family. Similar studies have also found that the prolonged hospital stay required for the entire intensive treatment is not tolerated by patients, especially when their symptoms have improved or they have a powerful incentive to return to home, work, or study (Whitehouse 1980). For this reason, among others, there is strong support for ambulatory treatment for the entire course of therapy (Banerjee 2000, Fox 1988).

Studies have also found that non-adherence can be up to three times higher in patients who are offered hospitalization but reject it. These patients tend to perceive more constraints and hold a more negative image of TB (Liefooghe 2001).

Finally, it has been suggested that using combination medicines three times a week, instead of the more common daily regimen, increases compliance rates (Whitehouse 1980), although strict direct observed therapy is essential with this strategy. A study in India found this to be the case, reporting a non-adherence rate of only 3% and high treatment success rates (Rodger 2002). Greater biomedical research needs to be done to fine more effective anti-tuberculosis drugs that will allow treatment regimens to be shorter.

7.3 Knowledge of TB

The overall Knowledge Score of the participants clearly shows that families and caregivers of TB patients have a low level of knowledge (mean 8.5 ± 1.90, range 3 to 16). Scores were low in all families, regardless of group (adherent or non-adherent). Not surprisingly, participants with a higher education had significantly higher Knowledge Scores. As described below, study participants had misconceptions on the causation, transmission and diagnosis of TB. They were somewhat more informed about the symptoms and treatment of TB.

Causation

Knowledge about the cause of TB was limited. Participants most commonly stated that they did not know what causes TB, and when they were able to provide an answer, they stated behavioural causes, such as smoking or drinking, environmental causes (including via the air), family inheritance, coughing, AIDS, or general body weakness. This is similar to results found in other African countries, particularly lifestyle and eating habits (Liefooghe 1997, Moloantoa

1982, Wandwalo 2000). Family inheritance was mentioned by a small number of participants, and is also a common finding in similar studies; however, it is difficult to discern if this is meant to describe a belief in true genetic inheritance or merely due to close proximity with family members (Liefooghe 1997). Spitting was mentioned by only one respondent; this was a surprising finding given the frequency of this social habit. A study in India found that spitting was the primary mode of transmission identified (Nair 1997). Only 9.7% of respondents stated that TB was caused by a microorganism.

Studies in other African countries have also differed in their explanations of the cause of TB. South Africans often attribute TB to poor nutrition, adultery, witchcraft, poisoning by enemies, and over crowding (Moloantoa 1982). These factors were also identified by participants in this study, but to a much less degree (less than 1%). Studies in other parts of the world find populations more knowledgeable about TB. In Sialkot, Pakistan, most people understand TB a contagious disease spread by sputum. Some people have misconceptions, but they differ from those found in this and other African studies (Liefooge 1995). Asian study participants often attribute TB to mechanical or physical causes, including lung injuries and cold exposure, or to "sins" (Liefooghe 1995). A study in India found that people were more likely to attribute TB to excessive worrying (usually about infidelity, disharmonious family relationships, or money issues), rather than to a biological cause (Nair 1997). People in the Philippines are more likely to attribute TB to poor living conditions or air pollution (Portero Navio 2002). These differences are likely explained by different cultural values and experiences.

Transmission

Misconceptions were also evident in participants' knowledge of disease transmission. The overwhelming majority stated that transmission occurred by sharing cups, plates, utensils, or food with an infected person. Again, this result is consistent with findings in other African countries (Liefooghe 1997, Thomson 1986). A Tanzanian study found similar results, but also identified unboiled cow's milk, blood contamination, and fecal-oral as routes of transmission (Wandwalo 2000).

No other studies were found that examined a population's view of who can acquire TB. Asking this question can provide useful insights into how people view a disease. In this study, the groups of people participants identified as likely candidates for infection reflects their view of disease causation and transmission. Participants most commonly identified poor lifestyle habits

and AIDS as causes of TB, and likewise identified those with unhealthy lifestyles and AIDS patients as likely to become infected with TB. Similarly, sharing and being in close proximity to infected people are the most commonly identified modes of transmission, and they also identified caretakers of TB patients to likely become infected with TB. Interestingly, a small number of participants stated that women or the elderly are more likely to become infected, possible reflecting a belief that these groups of people are weaker in the body than other (body weakness was also cited as a cause of TB).

Participants were also asked if they were more likely than others to get TB. This required them to apply their knowledge of the disease to their personal situation. Despite having firm opinions on who can get TB, more than half of the participants did not know if they were likely to acquire the infection. Surprisingly, almost three-quarters of participants feared that their family members were likely to become infected. Of the 21% that felt they were at a higher risk, their reasons for believing so were consistent with their beliefs of causation and transmission (notably closeness to the patient and other self-identified risk factors); 28% who felt they were not at risk of becoming infected either identified themselves as not having any risk factors, or felt that they were taking appropriate measures to protect themselves. This has important implications for family support. If family members believe that they are at a higher risk of getting TB because of their closeness to a TB patient, they may be more reluctant to provide support, including treatment supervision, to TB patients in their family. If family members of TB patients are taught how to protect themselves, they might be more willing to provide care and support to their patients.

Participants were generally understood how to prevent the spread of TB. Almost 90% of participants knew they could prevent transmission. This is significantly higher than that found in other African studies, where only 21% identified TB as preventable (Thomson 1986). This study did not ask participants how TB infection can be prevented, however other African studies have. Participants in a South African study stated that TB can be prevented by using health care services, decreasing alcohol consumption, and eating good food (Thomson 1986).

Symptoms

This study did not specifically ask participants to identify symptoms of TB, however, nearly all respondents stated that TB can cause severe damage to the lungs and can result in death. Other studies have tested the ability of participants to identify TB patients. A study in South Africa

demonstrated that almost a quarter of participants could not list identifiable characteristics of a TB patient. Of those that could, the factors most commonly listed were lethargy, pallor, and weight loss (Thomson 1969). Surprisingly, only a very small proportion mentioned cough, a very important finding, particularly in passive case finding TB system.

Diagnosis

Knowledge about diagnosis and the TB test was limited, as less than half stated that those exhibiting symptoms of TB should be tested. Almost 16% said that those who have already been diagnosed with the disease should be tested, and this could indicate a good understanding of the need for follow-up testing during the eight-month treatment. Other responses were variable, and demonstrate a lack of clear understanding regarding who should be seeking diagnostic care.

Despite this, participants generally understood that being tested for TB has benefits not only for themselves, but for their families. They cited excellent reasons for this, including: patients can seek treatment if they are found to be positive, precautions can be taken to protect the family if someone is found to have the disease, and having the test puts them in contact with a health care worker, allowing them to seek medical advice. Only 8.7% felt that having the TB test would not have any beneficial effects on the family, commonly explained by the fact that the TB test alone does not provide treatment.

This study did not examine health-seeking behaviour in detail, but it would be important to investigate this in future studies in western Uganda. Such knowledge could increase understanding of who seeks medical attention for their symptoms, and at what point in their illness they take action. This could lead to more targeted education and eventually help improve case-finding. Other studies have found that people with symptoms of cough, fever, loss of appetite and weakness, will often wait up to two months before seeking treatment; some would not seek treatment until they began coughing blood (Nair 1997). If similar data were found in Uganda, it could have important implications for future programme planning.

Treatment

The vast majority of participants understood that TB is a treatable, curable disease. This was found in another African study (Wandwalo 2000) but differed from Asian studies, in which

people often questioned the efficacy of the treatment (Nair 1997). This is an interesting finding in light of the fact that such a high percentage of TB patients die in the district, often due to HIV. In-depth interviews confirmed that Ugandans often distinguish between two types of TB: one that is associated with TB, and one that is not. The TB that is associated with HIV is often seen as "hopeless". It is understood that the TB not associated with TB is easily treated.

Study participants also understood the necessity of anti-tuberculosis drugs and did not believe that traditional healers can help with this disease, largely because they do not have access to the proper medications. Less than 3% of participants felt a traditional healer could be helpful by providing local herbs. Studies in other countries have shown a much higher reliance on traditional healers. A Philippine study discovered that local remedies and herbal products are seen as the main treatments for TB (Portero-Navio 2002), while a study from Malawi found that almost 40% of patients consulted a traditional healer before approaching a health care professional (Brouwer 1998).

In terms of treatment duration, only 22% of participants identified eight months as the proper length of treatment. The majority were either unsure or felt that the duration was much shorter. This is a concerning finding and indicates that family members, particularly ones that have been assigned the role of treatment supervisor, are not being thoroughly educated.

One Malaysian study examined where TB patients received their information. The majority of patients stated conversation with family and friends as their primary source. Only a small percentage stated that they had talked to a health care worker about TB. A study in the Philippines found this as well, but respondents also identified radio and television advertisements as primary sources (Portero-Navio 2002). In the current study, only 16.7% of participants stated that they sought information from a health care worker. This could be a misleading result since family members and caregivers of TB patients might have increased motivation to seek advice. Determining where other members of the community, including those with no association with TB, get their information could be useful in assessing the effectiveness of education campaigns. This could also be helpful in determining the quality and quantity of information dissemination, and in identifying subgroups for which targeted education campaigns should be designed.

7.4 Attitudes towards TB

Although some African studies have shown that TB is not as stigmatized as it is often believed to be (Westaway 1990), social stigma is a common identified as a concern in many developing countries (Johansson 1996, Nichter 1994; Liefooghe 1995; Liefooghe 1997). In the present study such a fear was shown to exist in Uganda, as indicated by the Attitude Score of participants (mean 3.1 ± 1.21, range 0 to 7). Attitude scores were lower in families with a non-adherent TB patient, but this difference was not significant. However, stigmatizing the disease or holding negative attitudes towards it may be one contributing factor to non-adherence. This stigma might be a result of the limited knowledge of TB in Ugandan families, decreased community awareness, social ostracism of TB patients, or a perceived threat of loss of employment, livelihood, or personal relationships.

Despite low Attitude Scores, participants exhibited a complete willingness to talk about the disease in both quantitative and qualitative study methods. This differs from studies in other parts of the world where TB is not openly spoken about and there is a reluctance to discuss the illness (Philippines) (Nichter 1994).

When participants were asked if they would want their neighbors to know if they had TB, almost 80% responded that they would, largely because it would either help prevent their neighbors from becoming infected, or they were hopeful that their neighbors would help them through their illness. This is not indicative of stigmatization, however it could reflect beliefs around the causation and transmission of TB; TB was not largely seen as a contagious disease, although "sharing" was commonly mentioned as a mode of transmission. For those participants who would not share their diagnoses with their neighbors felt so largely because they did not want to be socially ostracized or isolated, both of which are clear indicators of stigmatization.

Other studies find that participants stigmatize TB to a much larger extent. A focus group study in Pakistan found that the diagnosis of TB causes distress among the entire family; feelings of anger often resulted in a rejection of the diagnosis (Liefooghe 1995, Liefooghe 2001). This denial seemed to be based on the diagnostic label of the disease rather than on treatment-related issues. Patients would often ask that their diagnoses not be shared with friends and neighbors. African studies show similar results, in which TB patients either choose not to share their diagnosis or tell others a false diagnosis. An Ethiopian study found that this tendency resulted from a belief that TB is incurable (Gelaw 2001). In South Africa, this resulted from a fear of

social rejection (Westaway 1994). The issue of stigma is not restricted to developing countries. A study in California discovered that patients strongly stigmatized TB because of a perceived emotional and physical isolation from family and avoidance by the community; in response to this, patients tended to develop a sense of secrecy about their diagnosis and often chose not to share it with friends and neighbors (Kelly 1999).

Although most respondents in the current study stated they would share a diagnosis of TB with their neighbours, they expressed a large degree of fear and worry surrounding such a diagnosis. More than half of the participants said they were worried about acquiring TB, either because they feared they could not be easily cured or because they were closely associated with a TB patient and feared they would become infected. This seems to contradict the finding that most respondents felt TB was a treatable and curable disease. However, if participants are unsure of their HIV status, or feared they may be HIV positive, their views on TB would likely be quite different. Participants also tended to have an understanding of TB treatment in general, but when asked to comment on the affect TB would have on their own personal lives, they had much more negative attitudes.

An Ethiopian study found similar results in which more than 78% of respondents feared they would contract TB because of contacts with TB patients (Gelaw 2001). In the current study, many participants had a very defeatist attitude towards disease in general, believing they had no control over their health. These participants expressed no worry about getting TB, putting their faith in fate or God. A study in Ghana found that although TB patients were not likely to consult a traditional healer, they often turned to their church for healing (van der Werf 1990). This likely comes from intense cultural and historical experiences and provides a coping mechanism for the many difficulties they experience in their lives. Perhaps a good strategy to confront this would involve targeted education campaigns in churches and other faithful gatherings, involving both church and community leaders.

The finding that most participants were willing to share their diagnosis is surprising given the fact that the majority of them stated that their family would express strong negative emotions, including fear and hatred, if they knew they had TB. Family members with a non-adherent TB patient were more likely to believe their family would react negatively to such information. It is intuitive that if such negative feelings about TB are expressed within the family, patients will be reluctant to share their diagnosis and seek support.

Participants also had strong feelings regarding the social aspects of TB. More than half of the participants felt patients should be isolated, largely as a protective measure for the rest of the community. This is consistent with the fear and worry they express about the disease as well as their belief that TB is spread through sharing. Almost 7% of those who felt isolation was required stated that they felt that way because this is what they have seen in hospitals. However, practices in the hospital may be changing. A recent survey of Ugandan medical students in their final year at Makerere University shows that doctors do not believe that TB patients should be isolated from others (Emili 2002). Participants who felt isolation was not necessary stated that patients need the love and support of their family while they were sick, illustrating the strong sense of family and community in rural Uganda.

More than half of the respondents felt that having TB would affect their social relationships. Despite these negative emotions surrounding TB, respondents were equally likely to place blame on either weakness from the disease or social isolation as causes.

7.5 Family Support

Study participants tended to have higher Support Scores when compared to Knowledge and Attitude Scores (mean 5.4 ± 1.05, range 3 to 8). However, there was no difference in Support Scores between adherent and non-adherent families. Despite a lack of knowledge and the stigma attached to TB, families display traits that suggest they support their patients' treatment. Almost all participants knew that their patient took tablets for TB and could identify where they received them.

7.6 Gender and TB

Reports from Kabarole District in 2001, state that 60.7% of new TB cases were male, and in the present study, 51.7% of TB patients selected were male. This suggests, at least in the absence of any biological explanation, that both genders have relatively equal access to TB control programmes in Kabarole district. Although sputum conversion rates were not recorded in the present study, a recent Ugandan study reported no difference in this key indicator between the genders (Nsubuga 2002). Similar results have been found in other studies as well (Begum 2001).

Some studies have shown that women have increased adherence compared to men (Johansson 1999, Long 1999). However, this study showed no difference in adherence between men and women. In addition, female participants had significantly higher Attitude Scores than male participants, indicating that they stigmatize the disease to a lesser degree. Ironically, females also had a significantly lower Support Score, which is worrisome since women are often the primary caregivers in the family.

TB is an important infectious disease killer in Uganda. Considering the role of women as caregivers and mothers, and the fact that the health and welfare of children is closely linked to that of the mother, TB in women can have serious repercussions on the family. For this reason, it is essential that public health workers encourage all people, especially women, to visit a health unit for screening as soon as they exhibit symptoms of TB. When community outreach is conducted to educate people about TB, an effort should be made to illustrate the additional effects of infectious disease on women and the family. An approach to TB control should address not only the physiological differences between the sexes, but also the behaviours, expectations, and roles that exist within the Ugandan social, economic, and cultural context (Diwan 1999).

7.7 Effectiveness of DOTS

Although participants were never asked if the patient received DOTS, in-depth interviews confirmed that very few TB patients in rural western Uganda actually receive directly observed therapy, despite an expressed governmental commitment to the programme. Even in the sub-counties employing the DOTS strategy, half of the TB patients did not receive DOTS. In addition, reports to WHO illustrate weakness in the Ugandan programme. In 1999, 79% of the notified TB cases were registered under DOTS. Only 31% of cases completed the treatment and 30% were cured. The mortality rate was 7.8%. The default rate was 16%. It should be mentioned that in Uganda, a patient is labeled a "defaulter" after missing three months of treatment. This is quite insensitive when compared to the WHO standard. It was also estimated that only 27% of all estimated cases were successfully treated under DOTS, one of the lowest treatment success rates in all high-burden countries (Dye 2002).

Other developing countries also report problems with DOTS. An Indian study found that only 74% of TB patients received DOT, of whom 85% were men (Balansubramanian 2000). In this study, some patients chose not to participate in DOTS because of age or infirmity, or social

stigma. Those patients who did not participate had 26% treatment failure and 19% relapse, whereas patients who received DOTS had less than 3% relapse or failure.

DOTS has been widely recommended by experts and has been endorsed by both national and international health authorities as the standard of care for TB treatment. However, critics have questioned the appropriateness of DOTS on pragmatic, scientific and ethical grounds (Hill 2002). Reasons can be summarized as follows :

1. Poor acceptance by communities: Cultural and sociologic factors may hinder the acceptance of DOTS even in well-designed programmes, necessitating sustained, labor-intensive efforts at education and individualize support (Hill 2002);
2. It may consume scarce resources that could be directed elsewhere (Hill 2002);
3. Concurrent improvements in other aspects of previously ineffective TB programmes may actually contribute to DOTS' alleged benefit (Hill 2002);
4. Cost-effectiveness of building an infrastructure for DOTS in districts that already have good TB control (Hill 2002);
5. Supervision by a health worker may not be possible in many rural, low density, large distance situations; alternative forms of supervision are less well studied and presumably highly variable depending on the setting, the culture and the exact nature and relationship of the community supervisor; and
6. The ethical/human rights issue is that it may be perceived as intrusive and paternalistic, infringing on personal freedoms.

There is a general lack of critically designed trials to explore the efficacy of DOTS. The majority of scientific studies designed to evaluate the DOTS strategy are primarily comparisons with historical controls. In studies that have been conducted, it is difficult to extrapolate results since they represent distinct and diverse cultural settings. They represent programmes at various stages of development and populations with different incidence and prevalence rates, rates of HIV co-infection, and prevalence of drug-resistant TB. However, randomizing patients to receive either supervised or unsupervised therapy could be considered unethical, given the positive experiences with DOTS.

Despite this, several studies have been done, showing various results. An unblinded, randomized controlled trial (RCT) in South Africa compared direct observation and self-supervision. Interestingly, treatment for TB was found to be more successful among the self-

supervised patients, even with higher rates of treatment interruption, and at a much lower cost (Zwarenstein 1998). However in this study, treatment success rates were unacceptably low in both study groups indicating an inadequate TB program overall An RCT in Thailand found the opposite: patients receiving supervised therapy had significantly better cure and treatment rates (Kamolratanakul 1999). Another RCT conducted in Pakistan compared patients who randomly received either supervision by a health care worker, supervision by a family member, or self-supervision (Walley 2001). There were no significant differences in cure rates, completion rates, and default rates between the groups. However, care must be taken in interpreting these results. They could indicate that DOTS simply fails to improve outcome, or they could be indicative of a more widespread resource and structural problem that affect either type of care (Ormerod 1999).

One systematic review of studies that have been done have found that the net effectiveness of DOTS ranged from substandard to excellent, with the differences largely attributable to poor adherence (Hill 2002, Volmink 2002).

It would be beneficial to determine the extent to which treatment adherence contributes to programme success. If DOTS is applied correctly, non-adherence is then removed from consideration and any remaining failure should be the result of biological, and not behavioural, causes. In addition, a well-documented criticism of the DOTS strategy is that tremendous improvement in public health infrastructure and staff involvement accompanies supervised treatment. Laboratory methods are also improved, as are case-tracking, outreach to non-adherent patients, and contact investigation (Hill 2002). The ecological studies commonly found in the DOT literature cannot distinguish between all of these factors.

Directly observed treatment may be the most visible component of the DOTS strategy, but it is ineffective when the other structural aspects are not implemented. Studies in areas of war and civil conflict have successfully implemented DOTS, and state that its success was largely due to a commitment to the WHO recommendations, including adequate funding, clear objectives, experienced staff, a working laboratory with quality control measures, a regular supply of drugs, and good management structure (Rodger 2002). A recent survey of TB control programmes in the Democratic Republic of the Congo found that many of these structural aspects were missing (Moore 2002). This survey found that only 22% of all health care centers had copies of the official treatment guidelines. This is likely responsible to the large prescriber non-adherence

also found in the country: only 69% of new TB patients were prescribed correct drugs in correct dosages. The survey also found that there was no adequate stock/inventory management system in place, and this resulted in significant loss of drugs to theft and expiry. This is extremely detrimental to patient adherence, often leading to patients being forced to default or to buy drugs from private pharmacies. This in itself is a dangerous practice. The survey found that 32% of all private pharmacies were selling rifampicin without a prescription. This increases the risk of introducing drug resistance into the population. Finally, and importantly, this survey found a complete lack of NGO participation in TB control services, and a lack of donor support.

A similar study in Kampala, Uganda, found that there was not one single health care center that met all the standards for appropriate TB care, and only 24% of them adhered to WHO-recommended treatment guidelines (Nshuti 2001).

The findings of the Ugandan and Congolese surveys illustrate the many challenges that impede sustainability of TB control programmes. Weak political will, coupled with inadequate pre-existing health care infrastructure, make it very difficult to meet the goals of DOTS. Because of this, in addition to a lack of funding from local governments and donor countries, DOTS remains under-utilized in the countries that need it the most.

7.7.1 Community Volunteers vs Health Worker Supervisors

In response to these major logistic obstacles to DOTS implementation, practical new approaches have been sought. In communities where resources are scarce, population density is low, and DOTS cannot be based at medical centers or supervised by health care workers, some elements of optimal DOTS must be modified or adapted. One solution has been to employ lay community or family volunteers as the observers. This has been the strategy of the DOTS programme in Kabarole District. Although programme performance is less verifiable and probably less reliable, it is preferable to unsupervised treatment (Hill 2002)

In fact, studies in South Africa show that community volunteers can be as effective, if not more so, than health workers as DOTS supervisors (Wilkinson 1996, Wilkinson 1994, Coleman 1998). A retrospective cohort analysis in South Africa showed that the majority of patients on DOTS (55%) were supervised by a community volunteer, most commonly by shopkeepers (Wilkinson 1996). Completion rates for patients supervised by health workers and non-health workers were the same.

Another study determined that after recruiting stores, churches, and schools as treatment points, the average distance each patient had to travel to receive his medication decreased from 29.6 km to 800 m (Tanser 1999). This resulted not only in a huge increase in the proportion of patients receiving supervised treatment, but in a significant decrease in the burdens placed on hospitals and other health care centers.

In addition, programmes relying on community volunteers, as opposed to health workers, are more cost-effective. An evaluation of both approaches in Bangladesh confirmed that the programme using volunteers was 50% less expensive, with equal treatment outcomes (Islam 2002). The study also determined that with similar budgets, the volunteer programme could cure three TB patients for every two in the health care worker programme. Similar findings were reported in a South African study (Floyd 1997).

It is important to have community involvement in selecting volunteers. Programmes reporting success with recruiting community members attribute this success to providing a sense of empowerment and ownership, particularly when the communities are comprised of different ethnic or tribal groups (Rodger 2002). This type of community participation, in which individuals assume responsibility for their own health, in addition to the health of others, develops a capacity for them to contribute to their own community development (Getahun 2000). Involving TB patients and other members of the community also ensure that local cultural nuances are recognized and accounted for. Successful supervisors have insight into both the patients' individual social situation as well as the health beliefs inherent in the community (Dick 1996). Patients may feel more comfortable being supervised by a person of the same age, gender or ethnicity. The relationship between patient and supervisor may be an important factor in adherent behaviour.

In choosing community volunteers, the most important factor is the convenience of the patient, particularly in terms of distance (Coleman 1998). In fact, a systematic review comparing traditional DOTS with CB-DOTS found no differences between the two. However, CB-DOTS was found to be more effective when patients were given a choice of supervisor (Volmink 2002).

Interviews with South African community volunteers found that CB-DOTS imparted the following benefits to the patient and to the community at large (Coleman 1998). In terms of the patients, being supervised by a community volunteer meant that they were freed from hospitalizations and they could still fulfil their responsibilities to family, work or school. In terms of the community, it was felt that the whole community benefited by seeing patients being successfully treated and cured by their peers, which resulted in a more positive image of TB in the district, with decreased stigma, fear, and isolation.

However, introducing CB-DOTS raises several issues, possibly requiring different solutions in different cultures. There may be cultural issues in the choice of supervisor. It may be very inappropriate for a supervisor to be of a different gender than the TB patient, or to be of a different age or generation of the patient. There is also limited understanding as to what type of education or training would be needed. Is it more important to impart technical knowledge of TB treatment to the supervisor, or would the program be more successful if supervisors were taught the importance and necessity of their role? Communities that do not depend on health care workers for supervision may have greater difficulties in assuring a constant and reliable drug supply. Despite a reliance on community members for supervision, there would still be a need for health care unit involvement, not just to supply treatment, but to conduct TB testing and maintain TB registries as well. These challenges suggest that a strong TB programme must already be in place if CB-DOTS is to be truly effective.

7.7.2 Other Strategies for Improving Adherence

In countries with limited resources and a large burden on the health care system, new ways of improving adherence have been explored.

Incentives

A non-governmental organization (NGO) in Bangladesh implements a successful TB control programme in which a local community health worker (CHW) is chosen by the community and received micro-financing through the NGO. The CHW is trained to identify people with a chronic cough and sends sputum samples for testing. They provide drugs to all patients, free of charge, once they are diagnosed. During the first two months, the patient must report to the CHW daily, after which the patients are given one week's supply of drugs at a time. Before treatment is started, each patient must pay a small fee and sign a bond stating that they will complete the treatment. If they default from their treatment, they do not get their money back.

This programme sees consistent cure rates around 85%, with only 1.7% defaulting and 6% mortality (Mushtaque 1999).

A similar programme was run in a hospital-based programme in India (Hill 1992). Patients were required to pay a pre-payment, which was refundable upon completion of treatment. Fees were on a sliding scale and entitled patients to purchase their drugs for 60% the actual cost. 62% of patients who participated completed their treatment, compared to only 23% who did not participate. However, it was found that there was a direct correlation between the amount of deposit paid and treatment completion, indicating that poorer patients still run a higher risk of defaulting.

A study in Haiti offered free medical care to one group of TB patients, and free medical care plus financial aid, other material incentives to attend a monthly clinic, and aggressive home follow-up by trained village health workers (Farmer 1991). There were significant differences in mortality, sputum smear conversion, weight gain, ability to return to work, and in cure rate.

Several American studies have also looked at the benefits of providing incentives to DOTS patients (Davidson 1998, Salomon 1997, Smirnoff 1998). Some of the incentives offered included food coupons, public transport tickets, free phone and TV, healthcare insurance, methadone treatments, and HIV counseling. Compliance was still found to be low in all studies.

Of course, these strategies are not realistic options for most developing countries like Uganda, who are struggling to provide only the very basic necessities of care for TB patients. For this reason, food or bus fare incentives might be more realistic.

Supervision by a Family Member

Generally, this is not a strategy recommended for DOTS. In-depth interviews revealed that family members are never approached to be supervisors, largely because they may be more lenient with the patient, and protect them when they default from their treatment. Nevertheless, the feasibility of this option has been investigated in several countries. A retrospective study in Thailand found that over 86% of DOTS patients were supervised by a family member (Akkslip 1999). Cure rates reached 85.2% (vs 70.9% in self-supervised patients). Family members were each given a thirty-minute training session, and a health care worker visited the family weekly during the intensive phase and monthly thereafter. Such an option may not be possible in many

other countries; it requires not only sufficient staffing to conduct training and visits, but adequate transportation systems. Other similar studies have found adherence to be lower in patients being supervised by a family member (Banerjee 2000).

Supervision by Students

An Indian study evaluated the feasibility of recruiting student volunteers to act as treatment supervisors for TB patients (Rajeswari 1997). The students were trained through lectures, booklets, and group discussions. After passing a test, they were given practical training in drug delivery, defaulter retrieval, home visits, and record keeping. Students delivered drugs to each patient every week. Treatment completion rate was 83%, and the students were able to bring 57% of defaulters back to treatment. This strategy provides a good short-term solution, but may not prove to be sustainable, as students may become less reliable during exam time, vacations, and after graduation.

Educational Methods

A relevant study in South Africa describes a project in which local nurses held discussions with their TB patients to explore how they experience their disease (Dick 1996, Dick 1997). Information obtained from this process was used to develop a photonovel which was given to all newly diagnosed TB patients. The booklet dealt primarily with issues related to social isolation and stigmatization, and was found helpful to both patients and healthcare staff.

Counseling

Incorporating counseling into a TB treatment has been shown to have a significant impact on treatment adherence in Pakistan (Liefooghe 1999). Patients were randomized to either the intervention or control group. The intervention included counseling at the start of treatment and at each subsequent visit. Counselors belonged to the same socio-economic background as their patients. They received intensive training and learned how to anticipate problems or critical moments in treatment adherence, and how to activate the social network to involve family members in motivating the patient to take his drugs. Teaching locally-chosen members of the community to act in supportive roles could give TB patients in rural Uganda the extra motivation they need to adhere to their treatment.

TB Clubs

One village in Ethiopia developed a system of "TB clubs" (Getahun 2000). It started by giving all newly diagnosed TB patients follow-up appointments at the nearest health care center on the same day at regular time intervals. Patients got to know each other, and eventually formed themselves into formal clubs. A leader was appointed to encourage all patients to attend the clinic on their appointed day. These clubs met on a weekly basis to provide support to each other. These clubs were eventually recognized by the Ministry of Health, and educational materials were then provided to the club leaders. Through role playing and public meetings, this information was shared with the rest of the community. Eventually, this clubs expanded to become involved in referring TB suspects for clinical evaluation. These clubs were able to identify 69% of all patients and 76% of all sputum smear positive patients in their district, and resulted in treatment success rates of 83%. Clubs such as these can not only potentially improve treatment adherence, but may be able to address the stigma attached to the disease and gaps in knowledge community members might have.

7.8 HIV and TB

Although HIV status was not determined in this study, it is likely a contributing factor to the high mortality rate (9.2%) observed in this study. A previous study in Uganda found that 35% of HIV-positive patients died before completing treatment, compared with 11% of HIV-negative patients and 25% of those whose HIV serostatus was unknown (Glynn 1998). HIV has been shown to be a primary determinant of mortality, depending upon the severity of immune deficiency (Ackah 1995). Studies in other African countries illustrate the effect of HIV on TB mortality: One study in Ethiopia found HIV-seroprevalence to be 22% among smear positive TB patients, and determined that co-infected patients were significantly more likely to default from treatment (Tekle 2002). Another study in Zambia reported that 73% of TB patients were co-infected with HIV; during the course of treatment, a 35% mortality rate was seen in HIV-positive TB patients, compared to 9% in HIV-negative patients (Elliott 1995). This study also stated that deaths among HIV-positive patients contributed the highest number of failures to complete treatment.

Despite the clear connection between HIV and mortality in TB patients, more research should be conducted to determine the characteristics of TB patients who die before completing their treatment. Mortality rates have been found to be the highest during the first and second month of treatment (Banerjee 2000). Sputum smear negative TB and extrapulmonary TB have been

shown to have higher mortality rates, as well as higher rates of non-adherence (Banerjee 2000). Several explanations for this have been suggested, including: sputum smear negative patients are more immunosuppressed, and they may have been diagnosed with TB incorrectly and actually have an HIV-related, non-TB, respiratory disease that is not responsive to anti-tuberculosis drugs.

HIV co-infection impacts the gender bias discussed above. Studies that have examined gender relationships in TB patients have found a similar proportion of HIV infection among males and females in Tanzania, Zambia, and Kenya. However, among younger age groups, female TB patients were more likely to be HIV-infected that males, whereas the opposite was found in older age groups (Nsubuga 2002). This means that TB and HIV may have a particularly severe impact on young women in low-income settings where their primary roles are as caregivers and mothers. Indeed, the delays in care-seeking among women may be compounded by the stigma associated with HIV.

HIV co-infection in high prevalence countries changes the epidemiologic pattern of TB disease. The impact of HIV depends on several factors, including: the prevalence of HIV; the prevalence of TB in the general population (aged 15 to 49 years); rate of conversion from latent to active TB infection; the annual risk of infection; and detection and cure rate of smear-positive TB cases (Styblo 1991). In areas of high HIV prevalence, there is a higher incidence of smear-negative and extra-pulmonary TB, as well as higher mortality rates. Under these conditions, the accepted cure rate of 85% may not be possible (Glynn 1998).

It is important to consider the strong epidemiological, biological, and physiological connection between HIV and TB when designing disease control programmes. In countries with a high prevalence of co-infection, it makes sense to integrate HIV and TB control strategies. Many community-based care organizations focused on diagnosis and caring for HIV patients receive funding from NGOs, and could be expanded to include treatment for TB as well. However, a study assessing fourteen community health care organizations in Uganda, Zambia, South Africa and Malawi found that only one organization provided TB care and collaborated closely with the district TB programme (Maher 1997). Despite this, it was felt that many of the other organizations had the potential to integrate more TB services into their programmes. If such a strategy were employed in Uganda, it could help reduce the load on other over-stretched health

care facilities. Further research into the feasibility and cost-effectiveness of such a strategy is needed.

7.9 TB and Poverty

TB incidence is substantially higher in poorer settlements, reflecting the strong relation between poverty and TB (Portero-Navio 2002). Studies looking at urban African populations find their knowledge of TB is significantly higher than rural populations, illustrating yet one more disadvantage of the poor rural areas (Liefooghe 1997). Indeed, the present study found that poorer participants (indicated by not owning radio) had significantly lower Knowledge Scores. In addition, it has been shown that people in developing countries often view TB as a social disease affecting poor people, thereby contributing to the problem of stigma (Johansson 1996).

In all parts of the world, TB affects primarily the poor or marginalized members of society. Considering the fact that TB also largely affects the most economically active age group, and often results in loss of work or wages, being diagnosed with TB only exacerbates the poverty. The poor have a higher risk of developing TB, and then are often denied access to adequate care. A Haitian study also found that many important factors relating to patient outcome (including initial exposure to the mycobacteria, reactivation of endogenous infection, access to treatment, length of convalescence, development of resistance, degree of tissue destruction, and mortality) are determined chiefly be economic factors (Farmer 1991).

The WHO DOTS strategy acknowledges access to TB care as a human right and recognizes the contribution TB control makes to poverty reduction by reducing the socio-economic burden TB inflicts upon the poor (World Health Organization 2002). However more efforts need to be made to break the vicious cycle of poverty. In order for TB programmes to help alleviate poverty, those living in poverty must be able to access the programmes. The cycle of poverty illustrates how diseases cannot be considered in isolation from the social processes that maintain it. Insights into the economic burdens of disadvantaged people is an essential component in understanding non-adherent behaviour. For this reason, it has been suggested that there needs to be a shift in the paradigm of TB control from treating diseased patients towards enabling health (and all that this encompasses) in the community (Ogden 1999).

7.10 Developmental Impact of the Study in Uganda

This study aimed to benefit TB control programmes in Kabarole district in the following ways:

1. *Create more awareness about the importance of adherence to TB treatment.* This was accomplished in three important ways. First, the research team introduced themselves to the LC-1s (village leaders) prior to approaching participants. During these encounters, the project was explained, including the motivation for doing the project. The importance of adherence was emphasized, as was the fact that non-adherence is the largest barrier to effective TB control. The LC-1s were encouraged to share this information with their communities. Second, a visit was made to each health care center in the sub-counties visited. The health care workers often accompanied the research team into the field and were able to conduct visits to TB patients that they otherwise would not have been able to. Several health care workers commented on the importance of these visits and expressed the wish to be able to do this more. Third, the District TB and Leprosy Coordinator also accompanied the research team into the field. While questionnaires were being administered, he took the opportunity to gather other family members for a short education session on TB, nutrition, and general health.

2. *Promote dialogue within the family regarding support for TB treatment.* A portion of the questionnaire focused on behaviours toward the TB patient in the family.

3. *Address the negative social stigmatization attached to TB.* It is hoped that the discussions with community leaders, health care workers, and families will promote dialogue about TB within the community.

4. *Provide new information required to identify those patients who may become non-adherent and possible interventions to prevent non-adherence.* This study did not identify a reliable way to identify patients who are likely to be non-adherent. Non-adherent patients were of both genders, all ages, and all disease classifications and categories. Families of non-adherent patients had various levels of education and knowledge, came from a variety of socioeconomic statuses, exhibited attitudes ranging from very positive to very negative, and practiced a wide range of supportive behaviours. Although there were very few statistically significant differences between families of adherent and non-adherent TB patients, this study confirmed that there is still much work needed in order to promote TB control. The fact that this disease is still socially stigmatized and that families generally have low levels

of knowledge about TB indicates that current TB education efforts are not as effective as they could be. A summary of recommendations to improve these efforts can be found in the last section of this chapter.

5. *Identify strategies that can be used by the TB programme to engage spouses and family in supporting or supervising adherence to TB treatment and contribute to improved TB programme administration through better understanding of family factors for the adherence to treatment of TB.* Supportive behaviour was demonstrated in many families, despite the stigma associated with the disease and the lack of knowledge in study participants. Work must be done to eradicate the stigma attached to TB so that patients feel comfortable being open about their diagnosis with family and friends. Efforts must also be made to increase awareness about the consequences of non-adherence (for both the patient and the community). Ensuring that families understand how to protect themselves from becoming infected, how to recognize the symptoms of TB, and what treatment for TB involves, will help demystify the disease and hopefully contribute to reducing stigma.

The ultimate impact of improving adherence to TB treatment, increasing cure rates, and thereby decreasing transmission in rural Uganda, is decreasing morbidity and mortality from TB, and increasing quality of life. Because there is such a high prevalence of TB in Uganda, because it is a chronic disease, and because it primarily affects the most productive members of society, the control of TB is important for the general development of the population. Although most patients with TB in Uganda are male, TB imposes a significant burden of care on women, who are the primary caregivers in the family and within the health care system. Therefore, identifying and curing, and ultimately interrupting the transmission of TB will result in better overall health, the primary goal of the Ugandan government. Another potential benefit of this study is promoting a model of family support as a necessary tool in striving for health. Currently there is no involvement of the family during initial diagnosis, intensive treatment in hospital, or during the continuation phase of treatment.

7.11 Canadian Perspective

Until recently, the incidence of TB in Canada was declining at a steady rate[5], and in 1989, goals were set to eliminate the disease by 2010 (Morbidity and Mortality Weekly Report 1995). However, instead of seeing a continued decline, an increase in morbidity occurred (Long 2002). This disturbing trend can be attributed to several factors, including the HIV epidemic, increased transmission in congregate settings (such as health care facilities, child care facilities, correctional facilities, and homeless shelters), an increased rate of immigration to the industrialized world, and increased transmission within First Nations communities. Similar trends were seen in the United States. By 1993, rates of TB had tripled, particularly in New York City. Cure rates were less than 50% and up to 89% of patients were lost to follow-up. 27% were re-treated, and it was found that drug resistance increased from 10% to 23% (Morse 1996). All of this was the result of a fragmented health care system and collapse of the public health infrastructure.

Immigration from areas of high incidence has contributed to the resurgence of TB in many of the countries that normally experience a low incidence of TB (Lillebaek 2002, Talbot 2000). Since the 1960s, there has been a significant shift in the pattern of immigration to Canada. This trend signifies a corresponding shift in the disease profile that immigrants bring to their host country, the main effect being that the foreign-born now account for over 60% of TB cases in Canada. Surveillance data from the United States show that TB in the USA affects racial/ethnic minorities disproportionately. Asians are 16 times more likely to have TB, Africans eight times more likely, and Hispanics, Native Americans and Alaskan Natives five times more likely (Centres for Disease Control and Prevention 2000). It is unclear how many of these people immigrated with a latent infection, or how many contracted the disease in the USA.

Although national surveillance, screening, and treatment programmes should be in place to control the transmission of TB throughout communities in Canada, it must be remembered that the TB epidemic spans the entire globe, and is one of the most neglected health problems in the world. Wang (1989) states that "if there is a lesson for immigration policy and for long range planning in health services, it is that TB is a potentially life-long infection, that the migration of persons had epidemiological significance for decades after their entry into the host country and that effective control and ultimately eradication of this disease will not be achieved until the rest

[5] In the United States, from 1953 to 1984, reported cases decreased by an average of 5.6% per year (CDC Cor curr)

of the world has reached the same end." Nearly all (95%) cases and deaths (98%) from TB occur in developing nations, and TB control is one of the most cost-effective disease control strategies available. Despite this, TB control in developing countries receives only two cents for every ten dollars spent on health (Thomas 1995). Ultimately, improving the local TB programmes in other countries will reduce the number and proportion of immigrants who have TB when they enter Canada and other low-incidence countries. Canada plays an important role in global TB control as demonstrated by a commitment to the 2000 announcement of the G-8 Okinawa declaration of the goal to reduce poverty and disease by 50% by 2010.

CHAPTER 8 – STUDY LIMITATIONS, LESSONS LEARNED AND FUTURE RESEARCH DIRECTIONS

8.1 Study Limitations

8.1.1 Possible Biases

Selection Bias

Because of the logistical and socio-cultural difficulties involved in locating TB patients, selection of study participants was not always random. This means that the TB patients and their families chosen for this study may not be representative of all families with TB in Kabarole District. Patient characteristics for the entire district, as defined by the 2001 Annual Report, were similar to those of the study participants. However, there was an important difference: nearly 60% of TB patients included in the study were classified as sputum smear positive cases, but only 38.9% of TB patients reported to the NTLP in 2001 were classified as such. Therefore, the results of this study must be interpreted with caution.

The research team made every effort to interview the primary caregiver of each TB patient. When this was not possible, the questionnaire would be administered to someone close to the patient. This also introduces another bias – caregivers could have a completely different experience and understanding of TB than others in the family.

There was also a significant movement of patients and their families to other districts. Many of the patients listed in the register had moved, as had their primary caregivers or other close members of the family. This high loss of cases could be significant if there are important differences between families who relocate and families who do not. This also reflects an important and perhaps underrecognized problem in the delivery of DOTS.

Recall Bias

Recall bias could be important in two important ways. First, in some cases, it had been over one year since the TB patient in participating families had been receiving treatment. Participants may have had difficulties remembering certain details. Most of the survey questions were more general in nature, rather than quantitative or factual, so this is likely not a huge concern in this study.

Second, the presence of a foreigner may have influenced participants' behaviour during the study. Despite the researcher's previous cross-cultural experience and training, and constant efforts to be culturally sensitive, fundamental differences between the participants and the researcher may have affected data collection and analysis. The extensive participation of local research assistants at each step of the research process likely helped reduce this bias in the field. However, the personal biases and ideals of the researcher may have influenced the ambience of the work atmosphere. Participants may also have been reluctant to answer truthfully in the presence of a foreigner, particularly in regards to non-adherent or non-supportive behaviour.

Misclassification Bias

A very important, and likely, bias in this study is misclassification of adherence categories. Bias in both directions is possible:

1. When patients are recorded as "adherent" in the TB register, this indicates that they have received their full course of treatment from the health center or their DOTS supervisor. It does not necessarily indicate that they took their tablets on a consistent basis, particularly if they are not on DOTS. Therefore, even if patients are classified as adherent, they could truly be non-adherent. In fact, studies have shown that up to 40% of TB patients classified as adherent do not take their tablets and interrupt their treatment without the knowledge of health workers (Barnhoorn 1992). In addition, due to inconsistent reporting in the TB register, not all non-adherent patients may be registered as such. Finally, the definition of "defaulter" was insensitive in relation to the biological requirements for successful treatment.
2. There is significant movement of patients between health care centers and hospitals within the district, as well as outside the district. This means that patients may be receiving treatment at more than one institution. Patients may therefore be recorded as being non-adherent at the health care center in which they are registered, but in fact be receiving their treatment elsewhere.

This misclassification is likely to be differential, meaning that the degree of misclassification differs between the two groups being compared. In this situation it is difficult to predict the direction of the bias (either towards or away from the null hypothesis), as it is a result of a complex interplay involving differences in the sensitivity, specificity, and prevalence of non-adherence and adherence (Szklo 2000).

8.1.2 Fieldwork Challenges

Incomplete or Inaccurate Record Keeping

Another important limitation was the incomplete and inaccurate record keeping of the TB Control Programme. This made identifying and classifying patients as either adherent or non-adherent very difficult. Many of the patients identified as being a "defaulter" may not have been defaulters because he/she may have transferred to another health unit, was entered into the registry more than once, or was simply missed in the registry. Also, patients who were recorded in the registry of collecting their drugs on a regular basis does not necessarily indicate adherence – they may have collected their drugs but neglected to take them.

Tracking and Locating Study Participants

The greatest practical limitation in this study was transportation. Since we were looking for specific people identified through a central registry, transport out to remote villages was necessary. There were several days where we would drive all day just to administer one or two questionnaires. As a result, transportation was more expensive and time-consuming than initially expected. The host institution (BHS) provided a vehicle and driver whenever possible; the rest of the time the research team had to rely on local transportation, which was not always dependable. In addition, there is no formal address system in the rural villages, so tracking down some of the participants was challenging.

8.1.3 Methodological Issues

Study Design

This study was designed to explore the role of family support in promoting adherence to TB treatment, under the assumption that Kabarole District fully implemented DOTS. After discovering that DOTS was only sporadically used, and that many additional obstacles stand in the way of effective TB control in the district, it became clear that the question of family support may have been prematurely proposed. A feasibility study, exploring the current TB control system and identifying the strengths and weaknesses of the program, may have been more appropriate at this early stage of TB study in western Uganda.

Sample Size

The difficulty in finding the identified families, along with the short time timeframe for the study, meant that the sample size was small (n=207). This represents a major limitation in this

study. It may be difficult to detect statistically significant differences between the adherent and non-adherent families. Despite this, valuable information regarding TB patients and their families' knowledge and attitudes was ascertained.

Study Instrument

Another major limitation of this study was difficulty in identifying and measuring in a valid, reproducible way, the factors, behaviours or activities that are really important in supporting adherence to treatment. Although the questionnaire was pre-tested in Uganda before the formal study began, none of the questions had previously been piloted or pre-tested. Face and content validity were considered. However, because of the language barrier, it is difficult to know whether the intended meaning of the questions were understood by the participants. In addition, the Scores were derived from this questionnaire and were therefore also not validated.

8.2 Ethical Implications

This study topic necessitated careful attention to privacy and confidentiality, because TB can stigmatize those infected with the disease. Consequently, to avoid the identification of TB-positive patients by the public, we attempted to conduct all interviews in a neutral place. The intentions of the study were made clear to each participant to ensure that both their anonymity and the confidentiality of their responses would be protected. However, because of social hierarchies and family dynamics, this was rarely possible. In many cases, community leaders, elders, and senior members of the household were present during the interviews. In addition to infringing on the participants' privacy and confidentiality, this could have potentially influenced the participants' honesty in responding to our questions.

Since it is possible that participants may not have always been aware that their family member had TB, we had initially planned to obtain consent from the TB patients prior to approaching their spouses or family members. This was generally not possible. Many TB patients had either died, moved to another district, or were otherwise not available.

Another important challenge arose with the issue of confidentiality. Participants consented to the study under the impression that all answers would be kept confidential. To help ensure this, interviews took place in a private place whenever possible. However, this was not always possible, and participants often completed their questionnaires with an audience. In addition to breaching confidentiality, this may have affected the participants' responses.

8.3 Lessons Learned

This research study, particularly the experience of data collection in the field, provided numerous opportunities for a deeper understanding of the challenges faced by rural Ugandans. Although many governmental and non-governmental agencies support the work of TB control in Uganda, it is clear that more commitment is needed to attain acceptable TB control in this country.

The International Union Against Tuberculosis and Lung Disease (IUATLD), the Global Office of the United States Agency for International Development (USAID), and the TB Global Drug Facility (GDF) visited Uganda in late 2003 to review the progress the NTLP had made throughout the previous year (unpublished). This review found that community-based TB care was expanding in several districts, data management had improved, CB-DOTS had been implemented in 34 of 56 districts, proficiency of lab staff had improved, and anti-TB drugs were fully available at the district level. However, despite these improvements, there are still some serious constraints. There remains a significant lack of operating funds and human capacity to maintain the initiatives that have already been implemented. In addition, Although the treatment success rate has improved (56% in the 2001 cohort), it is still below the internationally recognized target of 85%. It is also estimated that case detection rates are around 50%, significantly below the target of 70%. This illustrates that there is a need for real government commitment to improve upon the infrastructure, finances, and human capacity of TB control in Uganda.

Perhaps most importantly, witnessing first hand the devastating effects of poverty, HIV and other infectious diseases confirms the notion that to improve the health of these people, a more comprehensive approach is needed. Targeting diseases individually cannot be effective as long as people still have to live under conditions of extreme poverty.

8.4 Future Research Directions

In light of the lessons learned during the course of the study, it is clear where the future research direction lies. Although it is important to uncover reasons why patients fail to adhere to their treatment, it may perhaps be time to turn the focus of research away from asking biological, sociological, and cultural questions, towards exploring alternative methods of providing healthcare to impoverished populations.

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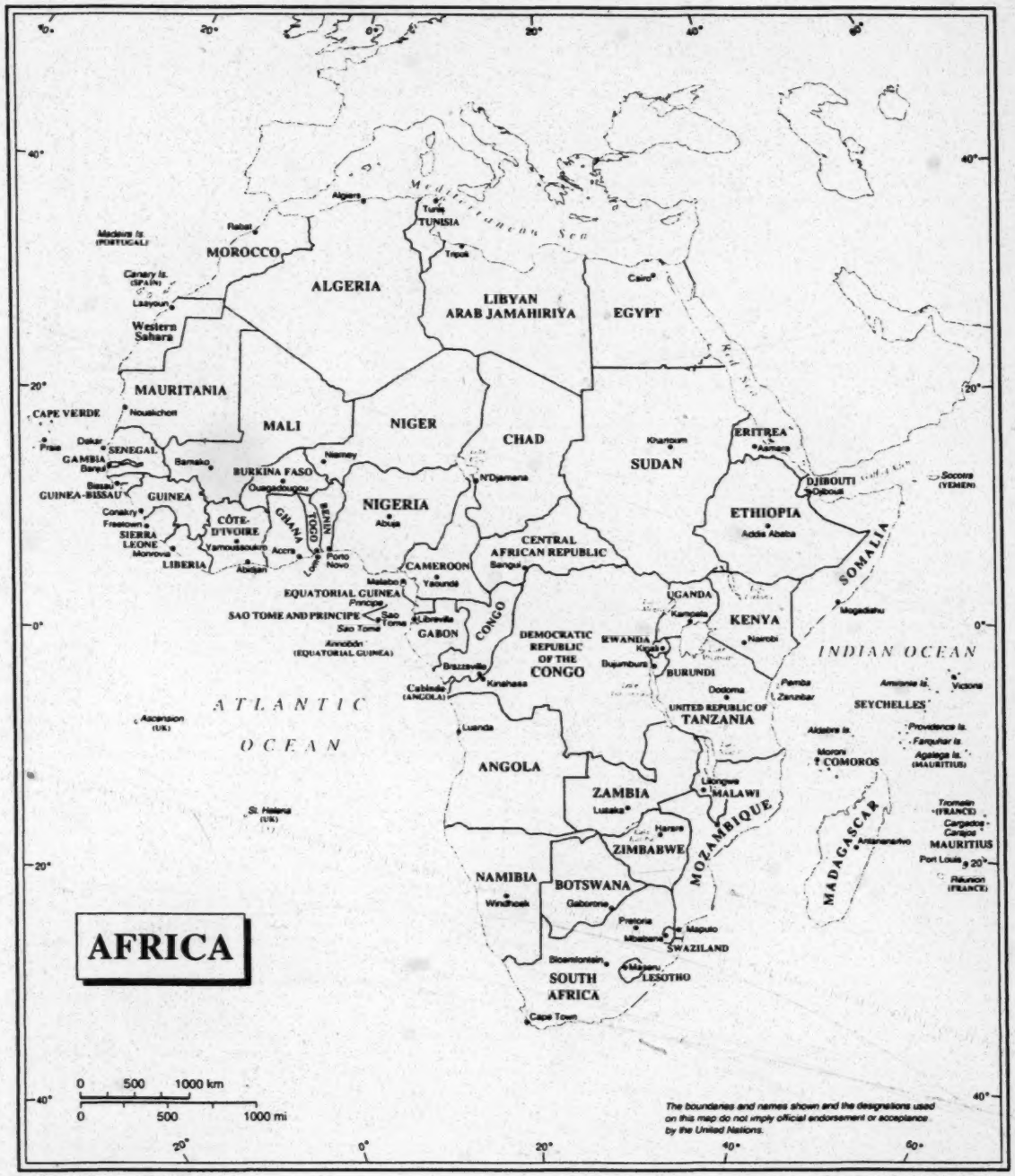
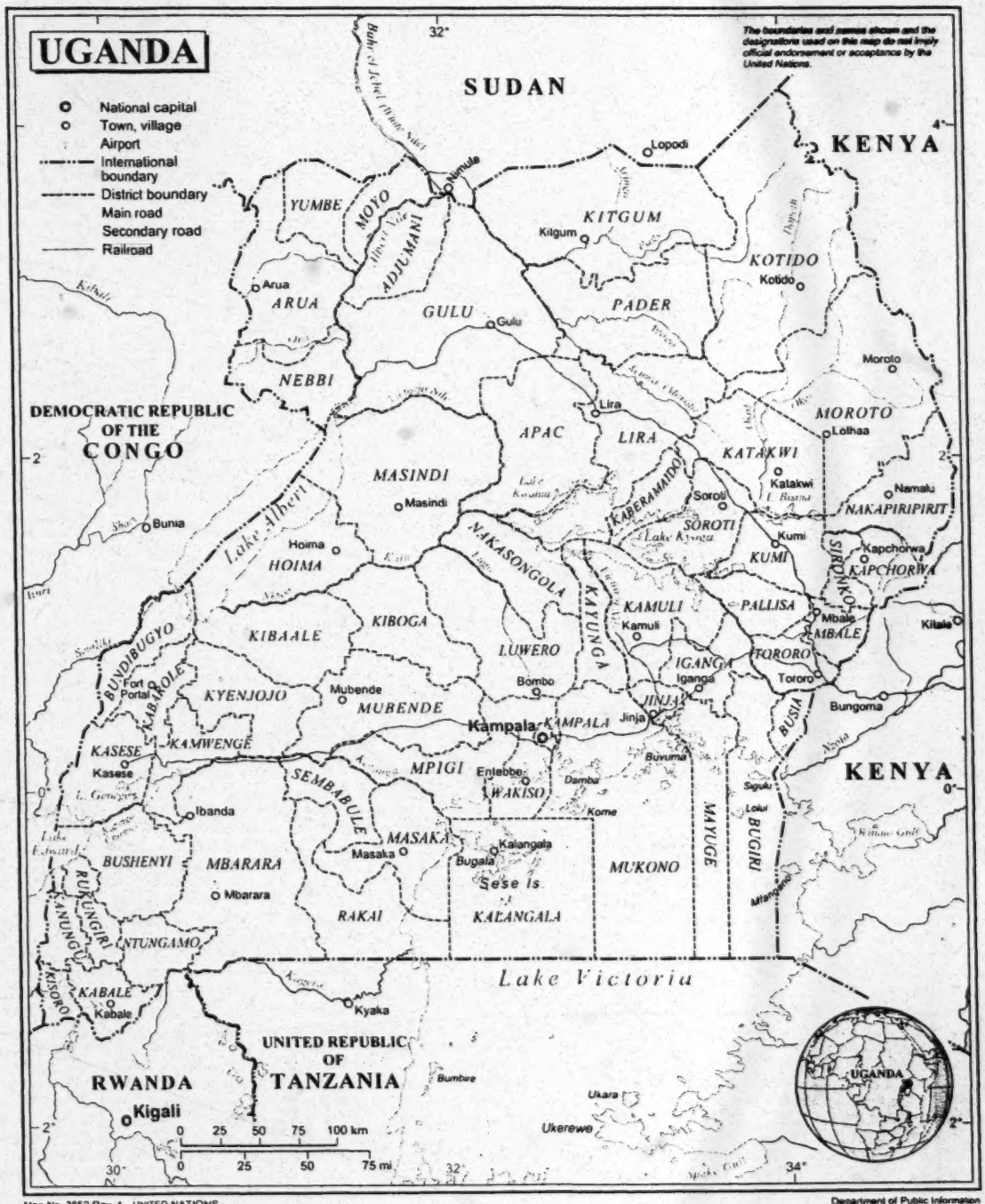
APPENDIX 1: MAP OF AFRICA



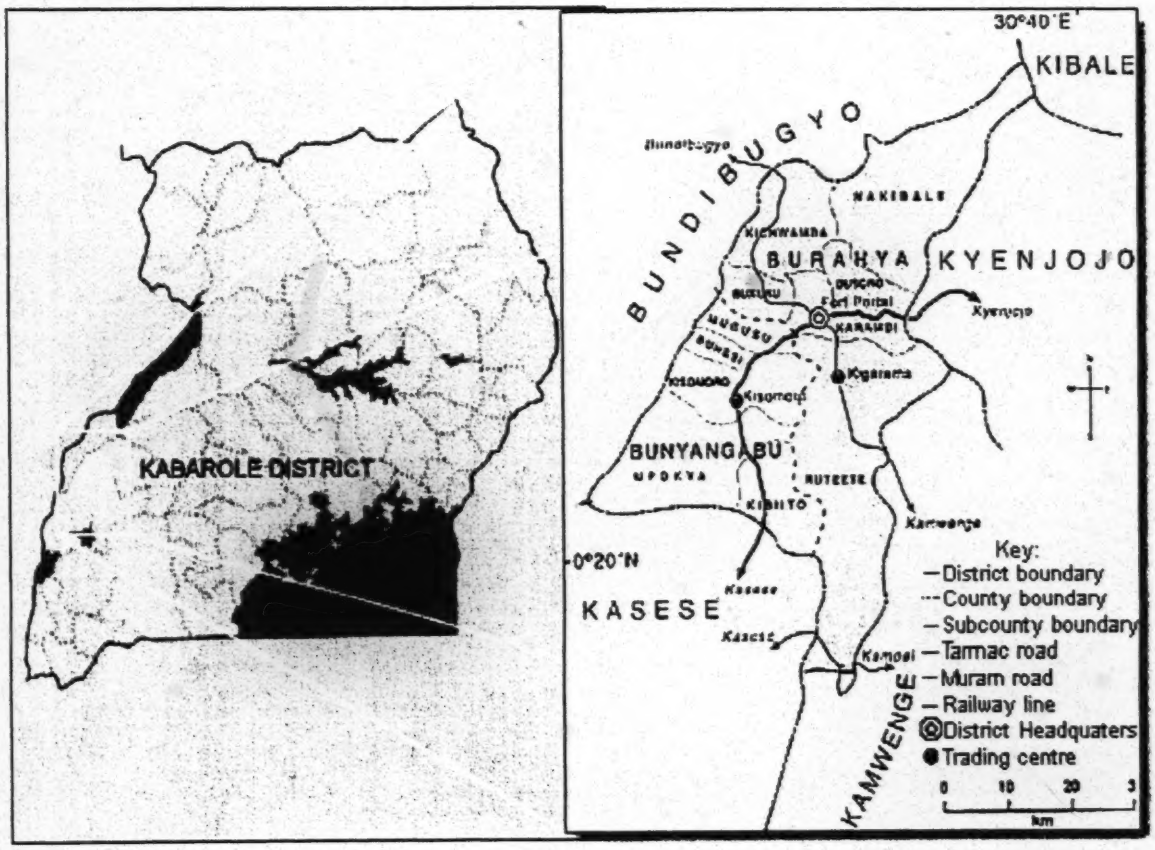
Map No. 4045 Rev. 4 UNITED NATIONS
January 2004

Department of Peacekeeping Operations
Cartographic Section

APPENDIX 2 – MAP OF UGANDA



APPENDIX 3 – MAP OF KABAROLE DISTRICT



APPENDIX 4: Dosage Schedules

Category I: Number of Daily Tablets Based on Weight and Medication

Month of Treatment	Medication	Weight in kg		
		< 32	33-49	>50
1-2 Intensive phase	**{RH}** R 150 mg H 100 mg (combined tablet)	2	3	3
	Z 400 mg	2	3	3
	E 400 mg	2	3	3
3-8 Continuation phase	**{EH}** E 400 mg H 150 mg	1	1.5	2

Category II: Number of Daily Tablets Based on Weight and Medication

Month of Treatment	Medication	Weight in kg		
		< 32	33-49	>50
1-2 Intensive phase	**{RH}** R 150 mg H 100 mg (combined tablet)	2	3	3
	Z 400 mg	2	3	3
	E 400 mg	2	3	3
	S 1 g	0.5 g	0.75 g	1.00 g
3 Intensive phase	**{RH}** R 150 mg H 100 mg (combined tablets)	2	3	3
	Z 400 mg	2	3	3
	E 400 mg	1	1.5	2
4-8 Continuation phase	**{RH}** R 150 mg H 100 mg (combined tablets)	2	3	3
	E 400 mg	1	1.5	2

Category III: Daily Doses for Children

Essential anti-TB Drug	Recommended Daily Dose
Isoniazid	5 mg/kg
Rifampacin	10 mg/kg
Streptomycin	10 mg/kg
Pyrazinamide	25 mg/kg

APPENDIX 5 – INDICATORS FOR TB CONTROL

From An Expanded DOTS Framework for Effective TB Control, WHO 2002

COVERAGE	DESCRIPTION
National: • Number (%) districts using DOTS • Population living in areas covered by the DOTS strategy	Surrogate for population coverage by DOTS strategy.
District: • Number of health facilities with DOTS services or total health facilities	Particularly public facilities, but may include NGO or private sector facilities.
DETECTION	**DESCRIPTION**
Health facility/district: • Number of symptomatic patients detected with cough > 2-3 weeks per total outpatients	Needed for resource planning.
• Number of smear positive cases detected per number of symptomatic cases detected	Needed for resource planning and is a surrogate for TB frequency and trend in the community.
Lab: • Number of smear positive examinations done for diagnosis • % positive slides for diagnosis	Indicates workload and case detection for resource planning. Over the same conditions, trend over time can indicate the trend of TB.
Regional/state/national • Number of new smear positive cases detected per number of estimated new smear positive cases • Number of total new cases detected per number of estimated new cases	To be compared with WHO target of 70% case detection.
QUALITY OF DIAGNOSIS	**DESCRIPTION**
Health facility/district: • Number of smear positive pulmonary cases per total pulmonary Tbcases • Number of smear positive cases per total TB cases • % discordance for positive smears and for negative smears	Indicates whether clinicians are using micropscopy or clinical /X-ray in TB diagnosis and the priority of smear positive cases in diagnosis and detection of TB. Indicates quality of microscopy exams.
TREATMENT OUTCOME	**DESCRIPTION**
Cohort analysis of registered smear positive new cases: • % cure, % treatment completion, % failure, % death, % default, and %	Should be done for all patients registered during a specific time period, on a quarterly basis.

transfer out • % treatment success = % cure + % treatment completion	To be compared with WHO's target of 85% treatment success rate.
Cohort analysis of re-treatment smear positive cases by category: • relapses • treatment failures • treatment interruptions • chronic or multi-drug resistant cases	
Sputum conversion rates: • % of all TB patients who are smear negative at the 2^{nd} – 3^{rd} month of treatment	Early surrogate for treatment success.
EPIDEMIOLOGY	**DESCRIPTION**
Annual incidence of smear positive cases and total cases	Incidence: number of new cases per population year.
Age and sex distribution	Distribution of numbers and rates.
TB meningitis in children under 5 years of age	Surrogate for transmission of TB in the community with a constant level of BCG coverage.
TB mortality rate	
Annual risk of TB infection	
HIV sero-prevalence rate in TB patients.	Estimated through survey or surveillance.
Drug resistance prevalence	
ECONOMIC ANALYSIS	**DESCRIPTION**
Cost per patient treated	To compare the efficiency of budget usage between various implementation sites.
Cost per patient cured	Cost-effectiveness measure to establish efficiency of resource use in relation to outcomes.
Cost per life saved	
Total required funding per fiscal year, total available funding and funding gap	Any funding gap with diminish the probability of programme success.

APPENDIX 6 LETTER – INFORMATION LETTER FOR STUDY PARTICIPANTS

Project title:	The role of spousal/family support in treatment adherence to tuberculosis in western Uganda
Principle Investigator:	Dr. Walter Kipp, Public Health Sciences, University of Alberta, Edmonton, Canada
Primary Associate:	Michelle Tubman, Public Health Sciences, University of Alberta, Edmonton, Canada
Co-investigators:	Mr. Tom Rubaale, Team Leader, Health Department, Kabarole District Administration, Fort Portal, Uganda
	Dr. Colin Soskolne, Public Health Sciences, University of Alberta, Edmonton, Canada
	Dr. Stan Houston, Infectious Diseases, University of Alberta, Edmonton, Canada

Date: September 2003

You are being asked to participate in a study that will look at how family members can help their loved ones take their tuberculosis medication so they can be cured from this disease. The study is being done by Kabarole Health Department, Fort Portal; Makerere University, Kampala; and the University of Alberta, Edmonton, Canada.

Purpose of the study:

The purpose of the study is to have a better understanding of why many tuberculosis patients do not finish their treatment. We would like to know how family members can help tuberculosis patients finish their treatment. This information is important to improve the tuberculosis treatment programme so that more people can be cured from this disease and so that the disease with not be transmitted to others in the family and the community.

Procedures:

A trained interviewer will ask you questions from a questionnaire. You will also be asked to participate in an interview or a group discussion. The questions and discussion topics with be about your experiences and troubles and with tuberculosis and how tuberculosis affects your family. The questions will be asked in Rutoroo. Answering questions from the questionnaire will take you about 30 minutes. The group discussions will last for 1 hour. Interviews and discussions will take place outside of your home at a place where you can choose. If you need some help with this choice, the interviewer will help you. The interviews will be audiotaped.

Possible benefits:

At the end of the questionnaire, the interviewer will ask you if you have any questions about the study or about tuberculosis. If the interviewer cannot answer the question, he or she will refer you to someone else who can answer your question.

The information from this study will help the Kabarole Health Department improve tuberculosis treatment services for your community. This will mean that many people in Kabarole and Uganda could benefit from this study. You may learn more about TB and its treatment which could benefit you and your family.

Possible harms:

It is possible that participation could lead to identification of your spouse or family member as a TB patient. We will make every effort to avoid this possibility. We do not want you to feel any stress or pressure about sharing information with us. If you feel badly while you are participating, please remember that you can leave at any time or refuse to answer any questions and you will not be affected in any way. If you feel badly after you have shared information with us, and you feel upset about it, please tell us. Incase you cannot contact us, please seek help in the Health Information Centres in Fort Portal or Kamwenge. If you want, we can also make arrangements for you to receive help from trained counselors at these Health Information Centres. Tom Rubaale, one of the investigators, is also available at the Health Development in Mucwa, Fort Portal, to answer any of your questions or to hear any concerns you had with your participation in the study.

Confidentiality and voluntary participation:

All records will be kept private. None of your answers will have your name on it. The questionnaires and the information from the group discussions will be kept in a secure area. Only Mr. Rubaale and Ms Tubman will have access to the information you give.

We will report to the Kabarole Health Department and the Ministry of Health in Kampala what we learn from this study. We will not tell them what any individual said. We will tell them only about the comments of the whole group of participants in general. We will never use your name. Nobody will know the response came from you.

You are not required to participate in this study. You do not have to answer any question which you do not want to answer. You can also leave the study at any time you want to, without fear that anything bad will happen.

For more information on the study:

If you have any concerns about the study or would like to have more information, please contact Mr. Tom Rubaale at the Health Department in Fort Portal.

Your consent and legal rights:

Your signature means that you understand the information in this letter. It also means that you agree to participate in this study.

Please keep a copy of these pages in case you need them in the future.

Initials participant:

Initials interviewer:

Date:

APPENDIX 7 – CONSENT FORM FOR STUDY PARTICIPANTS

Project title:	The role of spousal/family support in treatment adherence to tuberculosis in western Uganda
Principle Investigator:	Dr. Walter Kipp, Public Health Sciences, University of Alberta, Edmonton, Canada
Primary Associate:	Michelle Tubman, Public Health Sciences, University of Alberta, Edmonton, Canada
Co-investigators:	Mr. Tom Rubaale, Team Leader, Health Department, Kabarole District Administration, Fort Portal, Uganda
	Dr. Colin Soskolne, Public Health Sciences, University of Alberta, Edmonton, Canada
	Dr. Stan Houston, Infectious Diseases, University of Alberta, Edmonton, Canada

Do you understand that you have been asked to participate in a research study?	Yes	No
Have you read and received a copy of the attached information letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had the opportunity to ask questions and discuss the study?	Yes	No
Do you understand that you are free to not participate or withdraw from the study at any time? You do not have to give a reason. This will not affect the future health of you and your family.	Yes	No
Has confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by: _____

I agree to take part in this study:

_____ _____ _____

Signature of research participant Date Witness

_____ _____

Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____

Signature of investigator or designee Date

APPENDIX 8 - QUESTIONNAIRE

The Role of Family Support in Promoting Adherence to TB Treatment in Uganda

Date: **Name of Interviewer:** **ID #:**

Information obtained from TB Registry:

Sub-county: _____

Sex of TB patient: _____ Male
_____ Female

Age of TB patient: _____

Default status: _____ Defaulter
_____ Non-defaulter
_____ Death before treatment completion
_____ Unknown

Class: _____Sputum-smear positive
_____Sputum-smear negative
_____Extra-pulmonary
_____Unknown

Category: _____ New case
_____ Relapsed case
_____ Treatment failure
_____ Defaulter
_____ Unknown

Study participants:

Gender: _____ Male
_____ Female

Age: _____

Relationship to TB patient: _____

Level of Education: _____ Primary
_____ Secondary
_____ Institution
_____ None

Demographic and Socioeconomic information:

1. How many people live in your house? _____

2. How many children live in your house? _____

3. Do any children under five years live in your house? _____Yes _____No _____Unsure

4. What district were you born in? Kabarole Kamwenge Kyenjojo Other

5. Do you own a radio? _____Yes _____ No

6. What is your primary mode of transportation? Car Bicycle Taxi None Other

7. Roof: _____ Metal _____Thatched

8. Floor: _____ Earthen _____ Cement

9. How many women are married in your compound? _____

10. a) Do you own any animals? _____ Yes _____ No

b) If yes, specify: _____

11. What is your primary source of income? _____

12. What is your monthly income? _____

Knowledge, Understanding, and Attitude towards TB:

1. Who can get TB? _____

2. a) Are you worried about getting TB? _____ Yes _____ No

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

3. a) Are you more likely to get TB than others? _____ Yes _____ No

b)If yes, why?

_____

_____

c) If no, why not?

_____

_____

4. a) Are you scared about getting TB? _____ Yes _____ No

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

5. How is TB spread?

_____

_____

6. What causes TB?

_____

_____

7. Can TB do severe damage to your lungs? _____ Yes _____ No _____ Unsure

8. a) If you got TB, would it prevent you from working? ____Yes ____ No ____ Unsure

b) If yes, what would you miss about work?

_____

_____

9. Can you die from TB? _____Yes _____ No _____ Unsure

10. Is it easy to get TB if one has HIV? _____ Yes _____ No _____ Unsure

11. Do you know somebody with both HIV and TB? _____ Yes _____ No _____ Unsure

12. Should people with HIV be treated for TB? _____ Yes _____ No _____ Unsure

13. What advice would you give to people with both HIV and TB?

_____

_____

14. a) If you have TB, can you prevent it from spreading to others?
_____ Yes _____ No _____ Unsure

b) If yes, how?

_____

_____

c) If no, why not?

_____

_____

15. Can TB be cured? _____ Yes _____ No _____ Unsure

16. How do you treat TB?

_____

_____

17. How long is the TB treatment? _____

18. a) Is it important to finish your treatment, even if you feel better?
_____ Yes _____ No _____ Unsure

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

19. a) Do you think traditional healers can cure TB? _____ Yes _____ No _____ Unsure

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

20. Have you had the TB test? _____ Yes _____ No _____ Unsure

21. Who should get the TB test?

_____

_____

22. Do you have TB? _____ Yes _____ No _____ Unsure

23. Is having the TB test painful? _____ Yes _____ No _____ Unsure

24. a) Will having the TB test help protect your family? _____Yes _____No_____Unsure

b) If yes, how?

_____

_____

c) If no, why not?

_____

_____

25. a) Would you want your neighbours to know if you had TB?
_____ Yes _____ No _____ Unsure

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

26. a) Should people with TB be separated from other people?
_____ Yes _____ No _____ Unsure

b) If yes, why?

_____

_____

c) If no, why not?

_____

_____

27. a) Would having TB affect your relationships with others?
_____ Yes _____ No _____ Unsure

b) If yes, how? If no, why not?

_____

_____

28. Do you fear that your family members might get TB? _____ Yes _____ No

29. How would your family members feel if you had TB?

_____

_____

30. If your family is worried about it, what do you do?

_____

_____

31. When you hear about TB disease, how do you feel?

_____

_____

32. How do you feel about an HIV/AIDS patient with TB?

_____

_____

33. a) What foods should a TB patient eat?

_____

_____

b) Why?

_____

Family Support:

1. Does the TB patient in your family take tablets? _____ Yes _____ No _____Unsure

2. Where do they get their tablets?

_____

_____

3. a) Does anybody assist him/her in taking their tablets?
_____ Yes _____ No _____ Unsure

b) If yes, who?

4. a) Has the TB patient in your family ever interrupted his/her treatment?
_____ Yes _____ No _____ Unsure

b) If yes, why?

_____

_____

c) What actions did you take?

_____

_____

d) Who convinced him/her to come back to treatment?

_____

_____

5. When does the TB patient take his/her treatment?

_____

_____

6. a) Did you ask for information from the health care worker?
_____ Yes _____ No _____ Unsure

b) If yes, what information did you receive?

_____

_____

7. Do you remind the TB patient in your family to take their treatment?
_____ Yes _____ No _____ Unsure

8. What do you do if the patient forgets to take his/her treatment?

_____

_____

9. a) Was the TB patient hospitalized for TB? _____ Yes _____ No _____ Unsure

b) If yes, did you visit him? _____ Yes _____ No _____ Unsure

c) Did anyone else visit him? _____ Yes _____ No _____ Unsure

10. a) Do you anyone else in the community with TB? _____Yes _____No _____Unsure

b) If yes, do you talk to them about it? _____ Yes _____ No _____ Unsure

Final comments or questions: